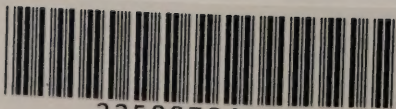


*DH Yearbook of Research
and Development 1990*

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DH Yearbook of Research and Development 1990



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Abbreviations

Abbreviations used in this *Yearbook* are given in full below:

ACTH	Adrenocorticotrophic Hormone
A&E	Accident and Emergency
AICD	Automatic Implantable Cardioverter-Defibrillator
AIDS	Acquired Immune Deficiency Syndrome
AIM	Advanced Informatics in Medicine (<i>EC programme</i>)
APT	Applied Potential Tomography
ARC	AIDS-Related Complex
ASN.1	Abstract Syntax Notation One
AWS	All-Wales Strategy
BAAF	British Agencies for Adoption and Fostering
BCG	Bacille Calmette-Guerin
BMA	British Medical Association
BMJ	British Medical Journal
BPA	British Paediatric Association
BSI	British Standards Institute
°C	Degrees Celsius
CA	Citizen Advocacy
CAD	Computer-Aided Design
CAL	Computer-Assisted Learning
CAM	Computer-Aided Manufacture
CAPD	Continuous Ambulatory Peritoneal Dialysis
CAT	Computerized Axial Tomography
CBS	Common Basic Specification
CCDG	Child Care and Development Group, Cambridge University
CCITT	<i>Comité Consultatif International Télégraphique et Téléphonique (EC)</i>
CCSC	Centre for Corporate Strategy and Change, University of Warwick
CCTA	Central Computing and Telecommunications Agency
CCU	Coronary Care Unit
CEA	Carcinoembryonic Antigen
CTFS	Corneal Transplant Follow-up Study
CHE	Centre for Health Economics, University of York
CMHT	Community Mental Handicap Team
CO ₂	Carbon-dioxide
COMAC	<i>EC Comité d'Action Concertée/Concerted Action Committee</i>
COSI	Central Open System Interconnection
COSIT	Central Open System Interconnection Team (<i>NHS</i>)
COVAS	Community Organizations, Voluntary Action and Social Welfare
CPN	Community Psychiatric Nurse
CPR	Child Protection Register
CRC	Cancer Research Campaign
CT	Computed Tomography
DE	Department of Employment
DoE	Department of the Environment
DH	Department of Health
DHA	District Health Authority
DHSS	Department of Health and Social Security, reformed into two separate departments in 1988
DNA	Deoxyribonucleic Acid
DPB	Dental Practice Board
DRG	Diagnosis-Related Group
DSA	Dental Surgery Assistant
DSRU	Dartington Social Research Unit, University of Bristol
DSS	Department of Social Security

DTI	Department of Trade and Industry
EEG	Electro-Encephalography
EORTC	European Organization for Research in the Treatment of Cancer
ESRC	Economic and Social Research Council
ESWL	Extra-corporeal Shock Wave Lithotripsy
EUROCAT	European Registry of Congenital Abnormalities and Twins
EWOS	European Workshop on Open Systems
FES	Functional Electrical Stimulation
FPC	Family Practitioner Committee
FPS	Family Practitioner Services
FTAM	File Transfer, Access and Management
GHQ	General Health Questionnaire
GHS	General Household Survey
GIFT	Gamete Intra-Fallopian Transfer
GP	General Practitioner
GPRU	General Practice Research Unit, University of London
GRE	Grant-Related Expenditure
GUM	Genito-Urinary Medicine
HA	Health Authority
HAA	Hospital Activity Analysis
HAS	Health Advisory Service (<i>NHS</i>)
HBV	Hepatitis-B Virus
HDL	High Density Lipoprotein
HEC	Health Education Council
HERG	Health Economics Research Group, Brunel University
HGH	Human pituitary source Growth Hormone
HGO	Hip Guidance Orthosis
HIPE	Hospital In-Patient Enquiry
HIV	Human Immunodeficiency Virus
HL-A	Histocompatibility Lymphocyte-A system
HMFG	Human Milk Fat Globule membrane antigen
HMSO	Her Majesty's Stationery Office
HSE	Health and Safety Executive
HST	Home Support Team
HTA	Health Technology Assessment
HTLV III	Human T-cell Lymphotropic Virus type III
IARC	International Agency for Research on Cancer, Lyon
IBM	International Business Machines
ICD	International Classification of Diseases
ICN	Infection Control Nurse
ICRF	Imperial Cancer Research Fund
IDU	Injecting Drug-User
IDDM	Insulin-Dependent Diabetes Mellitus
IMC	Information Management Centre (<i>NHS</i>)
IRC	Interdisciplinary Research Committee
ISO	International Organization for Standardization (<i>IT</i>)
ISODE	International Organization for Standardization Development Environment (<i>IT</i>)
IT	Information Technology
	Intermediate Treatment (<i>child care</i>)
IT & T	Information Technology and Telecommunications
IVF	In Vitro Fertilization
LA	Local Authority
LAMSAC	Local Authorities Management Services and Computer Committee
LAV	Lymphadenopathy-Associated Virus
LCMR	Liverpool Congenital Malformations Registry
LRF	Leukaemia Research Fund
LTS	Low Temperature Steam
LTSF	Low Temperature Steam/Formaldehyde
MCG	Magneto-Cardiography
MEG	Magneto-Encephalography
MEMO	Medicines Evaluation Monitoring Organization
MR	Magnetic Resonance
MRC	Medical Research Council
MRI	Magnetic Resonance Imaging
MRS	Magnetic Resonance Spectroscopy
n	Number
NCIB	National Collection of Industrial Bacteria
NCTC	National Collection of Type Cultures

NHS	National Health Service
NISW	National Institute for Social Work
NMR	Nuclear Magnetic Resonance
NMS	National Morbidity Study
No.	Number
NORDKEM	Nordic Clinical Chemistry Project, Helsinki
NPL	National Physical Laboratory
NPEU	National Perinatal Epidemiology Unit, University of Oxford
NPHT	Nuffield Provincial Hospitals Trust
NPRU	Nursing Practice Research Unit, University of Surrey
NRPB	National Radiological Protection Board
NSPCC	National Society for the Prevention of Cruelty to Children
OCA	Ophthalmological Clinical Assistant
OPCS	Office of Population Censuses and Surveys
ORLS	Oxford Record Linkage Study
OUP	Oxford University Press
PAA	Practice Activity Analysis
PAC	Public Accounts Committee
PACT	Prescribing Analyses and Cost
PAS	Patient Administration System
PC	Personal Computer
PCN	Percutaneous Nephropathy
PCR	Polymerase Chain Reaction
PCTA	Percutaneous Transluminal Coronary Angioplasty
PETA	Programme for Enabling Technologies Assessment and Application
PHLS	Public Health Laboratory Service
PKU	Phenylketonuria
PLAP	Placental Alkaline Phosphatase
PPA	Prescription Pricing Authority
PSA	Prostate-Specific Antigen
PSI	Policy Studies Institute
PSSRU	Personal Social Services Research Unit, University of Kent
QUALYs	Quality Adjusted Life Years
R&D	Research and Development
RAWP	Resource Allocation Working Party
RCGP	Royal College of General Practitioners
RCOG	Royal College of Obstetricians and Gynaecologists
RCT	Randomized Controlled Trial
REU	Racial Equality Unit
RHA	Regional Health Authority
RITA	Randomized Trial of Coronary Angioplasty versus Bypass Grafting
RNA	Ribonucleic Acid
RPMS	Royal Postgraduate Medical School, Hammersmith Hospital
SCPR	Social and Community Planning Research
SD	Standard Deviation
SERC	Science and Engineering Research Council
SHA	Self-Help Alliance
SHHD	Scottish Home and Health Department
SIFT	Service Increment for Teaching
SMD	Special Medical Development
SMR	Standardized Mortality Ratio
SPRU	Social Policy Research Unit, University of York
SQUID	Super-conducting Quantum Interference Device
SSADM	Structured Systems And Design Methodology
SSD	Social Services Department
SSI	Social Services Inspectorate
SSRG	Social Services Research Group
TCRU	Thomas Coram Research Unit, University of London
TEDBC	UK Trial of Early Detection of Breast Cancer
UCE	Unit of Clinical Epidemiology, University of Oxford
UK	United Kingdom
UKAEA	United Kingdom Atomic Energy Authority
UKCCSG	United Kingdom Childhood Cancer Screening Group
UKTS	United Kingdom Transplant Service
UMDS	United Medical and Dental Schools of Guy's and St Thomas's Hospitals, University of London
USA	United States of America
WHO	World Health Organization
WRL	Wolfson Research Laboratories, University of Birmingham

Brief Guide to Terms

Short, simplified explanations for some of the more complex or specialized terms used in the *Yearbook* are given below. These terms are highlighted in ***bold italics*** as they occur throughout the book.

Abstract Syntax Notation One (ASN.1)

ASN.1 is an international computer networking standard which allows any syntax to be specified in a formal manner, facilitating the exchange of data between the computers of varying manufacturers.

Assay

This is a test to determine the amount of a given substance or entity in a sample.

Computed Tomography (CT)

Also known as Computerized Axial Tomography (CAT), this is a radiological technique which uses an X-ray scanner to analyse 'slices' through the body. The slices are then digitized and integrated by a computer to produce a full, 3-dimensional image on the screen. The technique is used in diagnosis and is particularly suitable for distinguishing abnormal conditions in the brain.

Electronic mail

Often abbreviated to *email*, this is a computerized communications system. The user composes and sends a letter or message at one terminal; when the recipient keys into the system, it is reproduced and can be read at his or her terminal, located elsewhere.

Expert system

A computerized system which uses the techniques of artificial intelligence. Such systems are normally based on a set of rules, and are therefore known as rule-based or rule-set-based systems. By applying these rules, the computer program can estimate probabilities and so seem to be an 'expert' in a particular subject. Expert systems can usually justify their own line of reasoning in a manner directly intelligible to the enquirer.

Functional Electrical Stimulation (FES)

An orthopaedic technique in which electrical stimuli are applied to dormant nerves or muscles to produce movement: it is therefore of considerable functional benefit to the individual.

Monoclonal antibody

This is an antibody preparation consisting of only one particular type of antibody protein. Monoclonal antibodies are artificially manufactured from cell cultures derived from a single antibody-producing hybridoma cell.

Magnetic Resonance Imaging (MRI)

Magnetic resonance is the physical phenomenon in which protons (atomic nuclei) placed in a varying magnetic field will absorb energy at specific radio frequencies, depending on their local environment: protons in various biological tissues display different — characteristic — magnetic resonance.

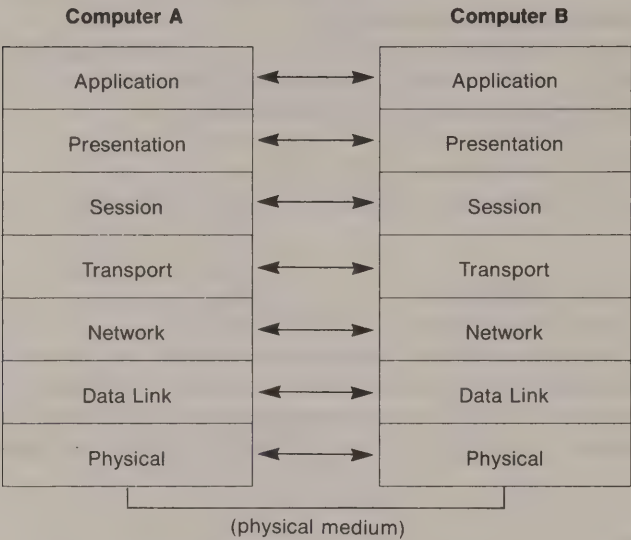
Also known as Nuclear Magnetic Resonance (NMR), MRI is an analytical technique which uses the characteristic magnetic resonance properties of protons to build up computerized cross-sectional images of the human body. It is primarily used for diagnosing cancer, vascular disease and brain abnormalities.

Open Systems Interconnection (OSI)

OSI is a general term covering standardized procedures for exchanging information between different manufacturers’ terminals, computers, networks, etc, which would otherwise be incompatible. *Open systems*, using the same basic model, are able to communicate with each other through their mutual recognition and use of applicable standards.

The current approach is represented by the *OSI Reference Model*, based on seven layers:

Figure (i): The Seven-layer Reference Model



Fundamentally, the first (*physical*) layer refers to the hardware which transmits signals around the network; layers 2–7 cover the software which directs what is transmitted; and the seventh (*application*) layer represents the program or application with which the user is working.

Packet switching

In IT, this is a way of transmitting information between computers. Messages are assembled into one or more *packets* – self-contained blocks of data, including address and control codes – which can be sent over a computer network and regenerated, in their original form, at the destination. Both OSI and electronic mail systems use packet switching to transfer data between remote computer terminals.

Reagent

Reagents are substances or solutions which are used to produce a characteristic reaction in chemical analyses.

Relational database

This is a mechanism for manipulating large database systems – often containing many files and records with overlapping data – which need to be linked or cross-referenced to provide various information.

Transducer

This is a device capable of converting signals from one physical form into another – for example, a microphone which converts sound into an electrical signal.

Illustrations



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Introduction

R&D 1989/90

Several important changes were introduced in the last issue of the *Yearbook*, all designed to make the publication more interesting, accessible and useful both to the specialist and to the general reader. A selection of short articles about work in the Health and Personal Social Services (HPSS) research programme appeared in Chapter 1; and Chapter 2 included abstracts for individual projects. The presentation of all the material was made clearer and more attractive.

The purpose of the *Yearbook* is to provide a comprehensive annual record of the research and development work sponsored by the Department of Health (DH), which will also give some impression of the range and depth of the studies undertaken. The three programmes directly commissioned by the Department are as follows:

- Health and Personal Social Services research programme (Chapter 5);
- NHS Information Technology research (Chapter 6); and
- Procurement Directorate research (Chapter 7).

Unlike last year, the account of the Department of Social Security's research programme will be published separately: this reflects the split in departments in July, 1988.

The main innovations of the last issue are retained or developed this year. Three groups of short articles are included in Chapters 2, 3 and 4. The first two sets relate to two of the Department's priority themes for research — AIDS and Child Care — and have been selected by the Liaison Officer responsible for that theme, in order to illustrate the range of work which is undertaken. The articles in the third group have been submitted by researchers in some of the Department's units, and are included as examples of some of this year's work. Abstracts for individual projects are again included in Chapter 5, and this innovation has been extended to work underway in Information Technology and Procurement Directorate (Chapters 6 and 7). This year, units and programmes have also been asked to provide a fuller account of their work, and in Chapter 1, Professor Francis O'Grady, Chief Scientist of the Department of Health until August 1990, has written a personal account of the HPSS research programme's development to date.

FINANCE

Total expenditure on R&D for which the Secretary of State was responsible amounted in 1989/90 to £60.1m. This covered the following areas:

	£m.
Research carried out by <i>non-departmental and other bodies</i> . The Department sponsors research in specific and discrete areas through a number of bodies including:	21.1

Public Health Laboratory Service Board
National Radiological Protection Board
National Biological Standards Board
Radiation Protection Research for UKAEA
Central Blood Laboratories Authority
Health Education Authority

	£m.
Locally-organized research conducted <i>within the NHS</i> and administered through regional research committees.	15.4E
Research <i>directly commissioned</i> by the Department of Health	
Health and Personal Social Services (includes £1m. for the MRC AIDS programme)	15.4
NHS Information Systems Directorate	2.2
NHS Information Management Centre	3.9
NHS Equipment and Supplies	2.7E
NHS Building and Engineering	0.1

E denotes provisional figures only

This excludes research commissioned and carried out by and in the NHS which is not covered by the locally-organized research scheme mentioned above, and expenditure on SIFT (Service Increment for Teaching — money which supports the costs of health services necessary for teaching and for research in the health-service-sponsored external funders).

DETERMINING PRIORITIES FOR COMMISSIONED RESEARCH

The priorities for research in the directly-commissioned HPSS programme are a reflection of its basic purpose: to provide objective information for Ministers as a basis for developments in health policy, improvements in public health, and increasing efficiency and effectiveness in health and personal social services. The programme also supports the NHS Management Executive in improving the effectiveness of the NHS. This has been an increasingly important focus for research during 1989, and the trend will continue with the recruitment of a Director of Research and Development for the NHS as well as for the Department of Health.

In 1989, the Departmental Research Committee (DRC) agreed seven themes as a framework for the Department's research priorities. These were as follows:

Acute Sector Hospital-Based Services

Research into service needs in respect of selected illnesses (cancers, cardio-vascular illness); into the finance, organization and quality of acute sector hospital services; and evaluation of the efficacy and cost-effectiveness of clinical procedures, drugs and equipment.

AIDS

Research to help prevent the spread of HIV; to increase understanding of how the infection is spread and how to avoid infection; to help with the development and evaluation of services for people with HIV. The objectives of this theme are pursued in part through collaborative arrangements with the Medical Research Council. (An overview of current work and future strategy in this area, by Dr Elizabeth Wilson, is included in Chapter 2.)

Child Care

Research into the adequacy and cost-effectiveness of services for children under five and for children in need of care and protection. (The article by Dr Carolyn Davies, included in Chapter 3, outlines the current and future research strategy for this theme.)

Community Care

Research into the development of community care for elderly people, mentally ill and handicapped people, and people with physical disabilities.

Primary Health Care

Research into the planning and provision of effective, efficient and acceptable primary health care.

Public Health

Research into the prevention of disease, prolonging life and promoting health. Priority is given to research concerning food safety, nutrition, environmental pollution and communicable diseases.

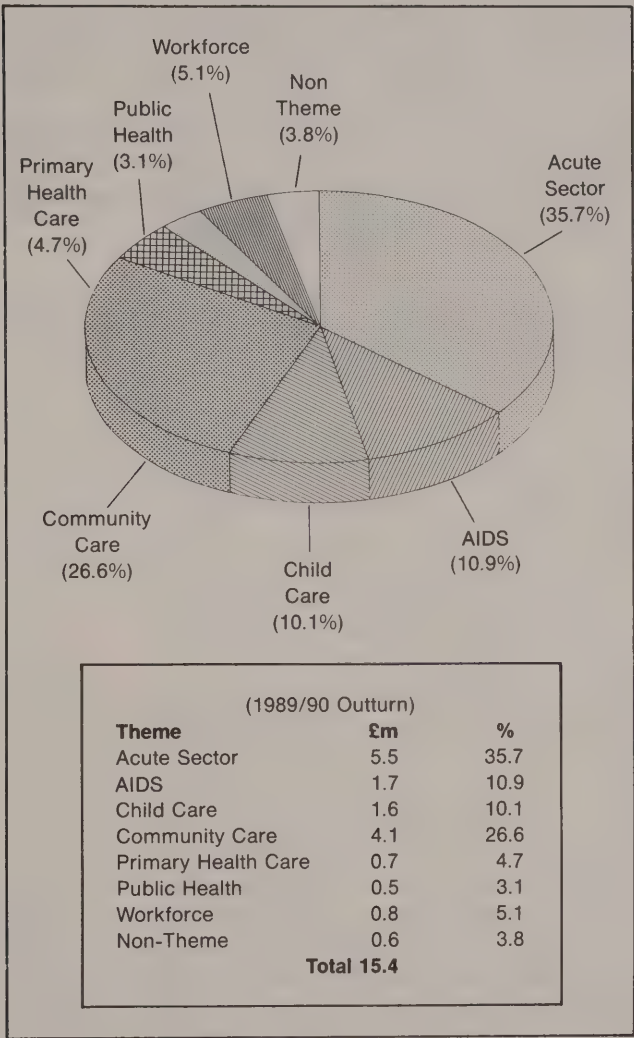
Workforce

Research into the education, training, recruitment, retention, remuneration and effective deployment of staff in view of current and future demography.

Research under these themes was carried out in units and projects based in universities, NHS authorities and other institutions.

The pie-chart shows how programme expenditure during the year was allocated between themes:

Figure (ii): Health and Personal Social Services Research Expenditure by Theme 1989/90



DEVELOPMENTS IN 1989/90

The major development in 1989/90 was the announcement by the Government in December 1989 that it intended to appoint a Chief of Research and Development (now renamed Director of Research and Development) with wide-ranging responsibilities. This announcement was made in response to the 1988 House of Lords Select Committee for Science and Technology report on 'Priorities in Medical Research'¹. The Select Committee recommended that the NHS should do more to identify and

meet its research needs. Although the Government did not accept the recommended means to this end, it was decided that research conducted in and for the NHS could be more effectively harnessed to improve patient care. In consequence, a new post — that of Director of Research and Development for the Department of Health and for the National Health Service — was created to direct the developments necessary to achieve this.

HEALTH RESEARCH FUNDED BY OTHER BODIES

During the year, the Department was represented on both the Medical Research Council (MRC) and the Economic and Social Research Council (ESRC).

The Department also maintains a special relationship — formally set out in a Concordat — with the MRC. The MRC has a principal public responsibility for biomedical research, both basic and applied. Through the Concordat, the MRC undertakes to consider the Department's views on research priorities in the development of its own research agendas, and to act to pursue research into health services on objectives identified by the Health Departments and agreed by the Council.

In addition, the MRC is responsible for coordinating epidemiological, clinical and basic scientific research on AIDS in the UK. The Department contributed £1m. to the MRC in 1989/90 for epidemiological research, which is one of the Department's most important priorities.

Reference

¹ House of Lords Select Committee on Science and Technology, Session 1987–88, 3rd report, *Priorities in Medical Research*. HL Paper 54 (1988)

Valediction

*A personal view from Professor Francis O'Grady, Chief Scientist of the
Department of Health 1986–1990*

The Department of Health has had four Chief Scientists, all very different — full-time, part-time, executive, advisory, physician, physiologist, psychiatrist, microbiologist — but all have been charged with the same task: to oversee the Health and Personal Social Services research programme designed to illuminate and advance the Department's development of policy. Now it is to be different. The Chief Scientist is to be replaced by a Director of Research and Development, who will have major responsibilities for research in the NHS, in addition to the duties of the Chief Scientist. It is a good time to take stock of the research programme's stage of development, and to review briefly how it reached this stage.

A BRIEF HISTORY

The Department of Health does not have its own research establishments. Small, in-house research groups existed for a time; in general, a central feature of the health research supported by the Department has been that institutions external to the Government have carried it out.

The origins of the programme can be traced back to 1958, when the Chief Medical Officer (CMO) had a small fund, and to the creation of a Departmental section concerned with research four years later. By 1967, there was a Departmental Research Committee to oversee the work and administer a budget of £750,000.

From the beginning, there was general agreement within and without the Department about three things. Firstly, the Department, working to advance the nation's health, needed a kind of research, unlike traditional medical research, comprising clinical, sociological and organizational elements. Secondly, the work was unlikely to be seen as prestigious by researchers, while — at the same time — it demanded skill-mixes which were in short supply and not likely to be assembled from existing research centres. Thirdly, to be influential, the research needed to be fully integrated into the Department's policy-making processes and closely linked to the delivery of services.

Powerful reinforcement of the view that the Department needed something different from traditional medical research, as typified by that of the

Medical Research Council (MRC), came from Lord Rothschild's report on arrangements for government-funded research. He concluded that the needs of government departments for applied science were not well-served by Research Councils preoccupied by the pursuit of excellence in basic research. In the case of health research, he proposed a transfer of funds to enable the Health Departments to become customers for research, which they would commission from the most appropriate contractors. The process would be directed and monitored by a newly-appointed Departmental Chief Scientist; and the new contracts would not necessarily go to the Research Councils. In fact, in the case of health, where it was acknowledged that much of the research needed by the Health Departments was outside the MRC's field, progressive dispersal of the funds might have been expected. Alternatively, since the principal criticism was that the Research Council had not been sufficiently attentive to the Departments' needs for applied research, the transfer of funds could have been seen as intended to drive a greater part of the MRC effort in the direction of more clinical and public health research.

In the event, neither the transition to the system Rothschild recommended, nor the process of establishing a coherent Departmental view of the most appropriate work for the MRC to undertake proved straightforward. In due course, the funds were returned to the MRC under the terms of an agreement — the Concordat — reviewed after five years in 1986, and due to be reviewed again in 1991. In the meantime, the Department's demands for research in fields outside those of the MRC had expanded considerably. As expected, it was found that the research base needed to meet those demands was small and insecure, and the Department had therefore established a series of research units, designed to meet its long-term needs, and respond flexibly to its short-term requirements.

The essential nature and needs of the Department's policy-based research programme have been accepted, debated, refined and progressed for over thirty years. How then does it come about that twenty years and four Chief Scientists after Rothschild, there remains a widespread perception that the Department's research programme has failed to match expectations? There are many contributing reasons, but major ones centre around confusion and conflict:

confusion about the basis and purpose of the Department's programme, and conflict between the interests and intentions of some of the principal participants.

Confusion

The first source of confusion is the belief, outside the Department, that its research programme exists to fund clinical research which is too close to service provision to command support from the MRC. This misunderstanding arises from the second source of confusion: the belief that the Department is responsible for the provision of services, and hence for the research necessary to advance it. It was plainly a surprise to the House of Lords Select Committee on Science and Technology in 1988, (perhaps, also, to the research community,) to be told that the Department's research programme, like the Department itself, exists to support its Ministers in their policy development. However, while the programme itself is rooted in policy development, evidence of its usefulness is sought in improvements in the provision of services. It was this apparent dichotomy — in which those who can effect change in service provision do not define research needs, and those who define the research needs cannot directly effect the changes supported by the research — which led to the recommendation by the House of Lords Select Committee that a distinct effort should be made to ensure that the research needs of the NHS were addressed directly and separately from the policy research required by the Department of Health.

The first main reason why the Department's research programme was not believed to be meeting its objectives, therefore, was that those objectives have been misunderstood. Its purpose was to support the need of policy development; but its critics claimed that it should have been supporting the clinical and operational needs of service provision.

Conflict

Apart from this confusion, conflict arose between the customers and contractors about the construction of the programme. Policy-makers find research useful when it illuminates and propels the policy development in hand. They need to turn in the relatively short term to agencies which will grasp what they are trying to do and provide quick and relevant responses. They are less likely to welcome agencies who want to debate the policy and its development, or the credibility of the proposals to advance it. Given the pressure of Government business, they are also unlikely to want to devote much time to developing a long-term research strategy, or contemplating questions for the future, which are more likely to preoccupy their successors.

The views and needs of researchers are almost the exact converse. They do not want to be 'penny-in-the-slot' responders: they wish to participate in the policy debate, and they want to develop long-term plans and to have time to speculate and innovate.

Whatever view is taken of the relative strengths of these positions, they plainly cannot coexist without

modification. It is easy to say that the trick is to strike a balance which optimizes the distribution of benefit. Failure to do so over a good many years has been the second major reason why the programme has been seen as less than a complete success from one or other side of the customer-contractor divide.

NEW STRUCTURES

These are, of course, not new revelations. Numerous attempts have been made over the years to get the balance right: to ensure that policy-makers were informed about research potential and their needs articulated in research terms; and to ensure that researchers acquired the skills and credibility which would enable them to respond efficiently to policy-makers' needs. The experiment in the 1970s with Research Liaison Groups (RLGs) was intended to provide the right kind of mix of policy-makers, research workers and research management to achieve the necessary interchange and planning. Some RLGs were very effective in tailoring proposals to the needs of their policy divisions. Their role was to advise the Department; but when they provided a coherent forward-plan, the forward spending pattern for research was inevitably fixed along established policy group lines. It became increasingly difficult to switch direction and, in particular, to deal with major, emerging cross-Departmental issues.

A radical solution was adopted in 1986/87. Distribution of funding along established lines was swept away, and a high-level Departmental Research Committee redefined the Department's research needs in terms of priority themes for work which was *currently* engaging the Department's attention. This had the great advantage of focusing the programme into broad but defined areas, and excluding or relegating others. But the programme is still subject to the danger of self-perpetuation, constraining the development of new initiatives, as well as to creeping expansion — with a little ingenuity, customers are able to fit most of their preoccupations into the theme framework. The priority themes do not themselves amount to a research strategy. They simply identify a series of boundaries, and the programme is still in danger of remaining a differently-packaged aggregate of discrete and disconnected policy needs.

Towards a research strategy

The scale and scope of the Department's policy concerns, and of research which underpins it, means that the construction of some 'grand design', in which all the elements are in place is most unlikely to succeed. Even if it were thought possible, it is not something on which policy-makers would be inclined to spend their time.

While a comprehensive strategy for the whole of the Department's work may be impossible, concentration on a limited number of themes provides an opportunity to devise a strategic plan for each. This offers the prospect of coherent advancement towards

defined goals in at least these areas. The themes themselves differ greatly in complexity and nature: some — the Acute Sector, for example — are so vast that substantial work on sorting out priorities within the theme was necessary before an overall strategy could be defined. But others, (AIDS is the simplest example,) are relatively accessible to the kind of analysis which asks what needs to be done, by whom and over what timescale: an approach which may provide a model for tackling more complex themes.

So far, two themes have been dealt with and two more are underway. The advantage of the theme framework, apart from mapping the way ahead and its probable financial consequences, is that its publication may improve the access of the research community to the Department's programme. Since the themes were first published in 1987, researchers have had some indication of the areas likely to command Departmental interest; but these areas are generally too broad to offer much guidance. The publication of more explicit needs within individual themes, as they become available, will expose the Department's plans to specific comment and criticism, and encourage approaches from researchers who believe they can make specific contributions.

Responsive mode

Does this mean that the Department is now beginning to invite approaches from the research community, instead of relying on a directed programme of commissioned work? The reality is that it has long operated a mixed system, in which the roles of customer and contractor could be rather loosely drawn. Over the years, although the Department's needs have been identified and prioritized in a variety of ways, the projects and programmes required to meet them have emerged from discussion involving the policy-makers who ask the questions, Research Management (RM) who help to shape them and identify likely contractors, and the research contractors themselves. Many researchers have also put spontaneous proposals to the Department and, clearly, those who have had previous contact with policy divisions knew what was likely to be of interest.

It might be complained, therefore, that the Department has fostered a privileged community of researchers, who won contracts and had a significant role in shaping others. In fact, not only did the Department welcome the accumulation of an expanding group of known and tried researchers, it also established a series of directly-funded research units. As the Department exposes more of its thinking, the number of researchers in direct contact with its needs should expand and that has to be to the benefit of both the Department and the research community.

RESEARCH UNITS

The substantial investment which the Department has made over the years in establishing and maintaining

research units can hardly have been what Lord Rothschild had in mind, in the days when he saw the Department shopping around for the best deals. It can still be argued that the Department has no business funding research facilities — that is the task of Higher Education Institutions and Research Councils. But, given the research base for the kind of work for which the Department is by far the biggest customer, progress would have been very slow without Departmental funding.

The history of the existing units funded by the Department is long and complicated, and the philosophies which guided their establishment and maintenance equally so. Many were established to meet contemporary needs in perhaps more expansive times, and many have subsequently been disbanded. As a result, the present stock is very mixed in size, subject area, degree of specialization — and extent to which they meet the Department's present needs. For a long time, there has been an uncertain boundary between designated units, intended to have a long life, and research programmes, which have grown accustomed to regular renewal. It remains important to make the distinction, in the interests of effective financial planning.

The units are supported by a six-year rolling contract, subject to a satisfactory two-yearly review — alternate reviews consist of a full day's visit, with comprehensive examination of achievement and plans by independent advisers. The expectation is that the contract will be rolled forward, subject to the important proviso that the work maintains both its quality and its relevance to the Department's priority needs.

For the future, it seems clear that units should exist only in areas where the Department sees an indefinite need for continuous, or successive, pieces of work in an area of continuing major concern. The Department must define the nature of the long-term need, and be certain that the collective expertise of the unit is appropriate to meet it. It is in the context of this long-term 'core programme' that the unit will build its national and perhaps international standing, make its contribution to the theoretical and methodological base of its subject, develop appropriate skills in the next generation of researchers and career opportunities for the unit members.

To further these aims, most of the units have been sited in Universities with the majority of directors and many staff holding honorary University appointments. If the relevant academic disciplines had expanded as hoped, the Department might have been able to pass on its units into academic keeping. But that has not happened, and it would not be altogether to the Department's advantage if it had. Despite the academic context, and the need to maintain and enhance their standing in their disciplines, the units do not enjoy the freedom of action that their locations might imply. In return for a secure environment in which to develop and expand their interests, units are expected to act as a store of expertise which the

Department can draw on in its policy development. When these needs conflict with the units' own perceptions of the most appropriate future development of their work, tensions of course arise in the arrangement, which calls for exceptional degrees of mutual understanding and trust. The most successful units show that this is possible.

Agreement about objectives may be lost in two ways. As the work develops, the unit may see the greatest opportunities for advancement in directions which lead away from the Department's interests — and they may be supported in this view by outside advisers on the periodic scientific visits. Alternatively, Departmental policy may develop and change in ways that require modification of the longer term research requirement. The situation can therefore arise in which the Department wishes to withdraw support from a unit which is continuing to make an acknowledged contribution to its field — but that field is no longer of priority interest.

Relatively large units covering a wide spread of Departmental interests are more likely to be able to adapt to such changes, while small or highly specialized units may not be. But the need for this kind of flexibility must be balanced by the dangers of long-term commitment of increasing proportions of finance, which progressively constrains the ability to support new work.

RELEVANCE

No systematic mechanisms for translating the lessons of all this research into service benefits have been established, despite the importance of doing so. Researchers are always being asked to try every method of ensuring that their messages reach the providers of services, not only other researchers in the field. But time on dissemination is time out of research; and it is asking a lot to expect those responsible for services to act on research which they did not plan, and for which they have not made any organizational or financial provision. Presentation of findings to providers whose minds and money are committed elsewhere is unlikely to exert decisive influence.

If research is to achieve its full benefit, service providers must be committed to it and to its implementation from the start. Money is one proof of commitment, and we have recently been experimenting by linking Departmental and regional funds in projects likely to have more than local value — in this way, maximising the effect of the project, and encouraging two-way traffic in ideas for implementation.

The House of Lords Select Committee on Science and Technology identified the lack of NHS involvement in both planning and using its own research as a crucial weakness of present arrangements. While it acknowledged the Department's need for policy-driven research, the Committee emphasized that the Department should do much more to foster the definition and implementation of research in and for

the NHS. There is no doubt that more needs to be done, but two points should be made. Firstly, research directed at the NHS, and at policy which relates to the NHS, cannot be neatly compartmentalized. Secondly, the Regions are independent agents and have always been free to support whatever research they felt necessary to pursue their own ends.

Responsibility for the Locally-Organized Research Scheme (LORS) was transferred in 1978 from the Department to the Regions. This is not the place to debate how useful the scheme has been: it is generally acknowledged that it has succeeded in encouraging many who might not otherwise have done so to engage in research. But it is interesting that — despite the Department's encouragement to do so — Regions spending their own money have on the whole not chosen to support the gaps in research identified by the House of Lords Committee. Many needs and opportunities are waiting to be exploited.

RELATIONS WITH OTHER BODIES

It seems obvious at first glance that there should be a fairly comprehensive picture of national investment in health research, which would guide the distribution and direction of activity amongst the many contributors to the field. In practice, there are substantial obstacles in the way of achieving this, and it is far from clear that doing so would be proportionately influential in determining the nature and progress of research. Many institutions, charities and industry, which are among the biggest spenders, are confined by their primary purposes to particular areas, and the possibility of modifying their research coverage in a major way is limited. Nevertheless, there is a strong argument for wider and more effective exchanges of information amongst the various agencies, which would encourage collaboration and productive distribution of effort.

The Department's formal relationship with the MRC was determined firstly by the transfer of funds in response to Rothschild, and then by their re-transfer in response to the difficulty of assigning them. The result has been that the Department has, in general, looked to the MRC for its wider interests in biomedical research, concentrating its own efforts on research designed to improve the efficiency, efficacy and delivery of services. Through the Concordat, the Health Departments have identified those areas where they would like to see a concentration of the MRC's scientific and clinical power. A series of developments, designed to improve the collaboration, will become even more important when the Department — through the Director of Research and Development's concerns with NHS programmes — becomes directly involved in areas which have so far been MRC territory.

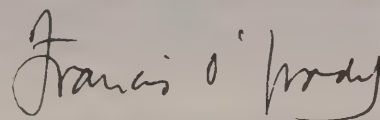
Much of the Department's need for research lies outside purely medical territory — in the social sciences and other disciplines, which are the concern of the Economic and Social Research Council (ESRC).

The ERSC's work in the health field is currently expanding, and opportunities for collaboration are likely to increase, in the context of NHS research. Finally, there is the large and expanding world of the medical charities — now collectively the biggest non-commercial spenders on health research. To date, the Department's discussions with them have been no more than exploratory, but again, with the Department becoming directly involved in service-related clinical research, both the need and the opportunities for collective and collaborative endeavour are likely to grow fast.

Many other topics, which have been peripheral to the Department's main interests in policy research, will become crucial in relation to its NHS interests. They include provision for the support of clinical

research, and much more direct involvement in organizational and financial provisions for the transfer of research findings into service benefits.

The many tasks added to those of the part-time Chief Scientist will certainly fill the other half of the time of the new Director of Research and Development. This is a particularly appropriate opportunity to wish the Director all success in sorting and mastering them.



Professor F. O'Grady
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Chapter 2

AIDS Theme Research

This section brings together nine articles, selected by the theme coordinator from the work in progress or completed during the year within the AIDS theme. It begins with a review of the development of the theme as a whole, the range and depth of the work undertaken, its application, and plans for the future.

Work on the theme began from a very limited research base in the mid-1980s, and is still at a relatively early stage of development. In the first phase, the issue of the future impact of AIDS on health and personal social services spending was of primary importance, and this is reflected in the range of studies which were funded. The strategy for the future, however, demonstrates that other questions will predominate as the programme of research matures. Some of the studies have been undertaken with single disciplines; in other cases, interdisciplinary teams have been developed to provide the new mixes of skills and approaches which the problems posed by AIDS research present.

The second article in this section is written by a *customer* for the research, working in the Department's AIDS Unit. It provides an insight into the processes which generate the need for research, and the ways in which research findings are fed back into policy-making.

The articles by McCann, and by the team from the Universities of Hull and York (Robinson *et al*) both illustrate some of the work which is being done to

underpin the *planning and development of services* to meet new needs. The project directed by Professor Pettigrew at Warwick is concerned with the *organization of services*, and will eventually assist the construction of guidelines for health authorities which are in the process of developing management systems to meet the demands of AIDS.

Several articles are centrally concerned with *costs*: the PSSRU article (Bebbington and Warren) focuses on local authority costs; and the cost of social service provision is also covered by the Hull-York project, mentioned above. Rees, on the other hand, examines costs falling on three health authorities as a result of providing HIV/AIDS services.

Finally, two articles report on research into the levels of *knowledge* about, and the *attitudes* towards AIDS found among service providers. Professor Freeling and his associates have concentrated on identifying the ways in which the vocational training offered to general practitioners in this area could be improved; while Foy and Gallagher report on the first national survey of general practitioners' knowledge, attitudes and behaviour relevant to the treatment of AIDS patients.

The views expressed in the following articles are those of the authors, and not necessarily those of the Department.

An Overview of Research on AIDS

The Acquired Immune Deficiency Syndrome (AIDS) is an eventual consequence of Human Immunodeficiency Virus (HIV) infection. AIDS was first recognized in homosexual men in the USA in 1981 who presented with diseases indicative of underlying immune deficiency. AIDS was first identified in the UK in 1981; the causative virus was discovered in 1983 and has subsequently been named HIV. It is spread in body fluids such as blood and semen.

In the UK, clinicians voluntarily send confidential reports of newly diagnosed AIDS cases to the Communicable Diseases Surveillance Centre (CDSC) in England and the Communicable Diseases (Scotland) Unit (CD(S)U). The UK cumulative total of AIDS cases up to 31 July 1990 was 3,548 (3,391 male, 157 female), of whom 1,925 (54 per cent) had died. Eighty per cent of the AIDS cases were homosexual or bisexual men, 6 per cent were haemophiliacs and 3 per cent Injecting Drug-Users (IDUs). The rest were the heterosexual partners of HIV-infected people, recipients of blood, the children of an at-risk or infected parent. In a small number, the risk factor is as yet undetermined.

The Department established an AIDS Unit in response to the growing public health problem posed by HIV and AIDS. Increasing future demands on the Health and Personal Social Services (HPSS) were anticipated, and the Department of Health AIDS research programme was started in 1984, to help define the impact of HIV and AIDS on the HPSS. Other government-funded research was also set up to study different aspects of HIV infection; for instance, the Medical Research Council (MRC) has two programmes of AIDS research:

- the Directed Programme is aimed at finding a vaccine to prevent and drugs to treat HIV infection;
- the Strategic Programme studies the clinical aspects, diagnosis, epidemiology (prevalence and pattern of spread) and treatment of HIV/AIDS.

The Department's AIDS theme research falls within the general remit of its R&D programme: that is, to improve the efficiency and effectiveness of the Health and Personal Social Services by improvements in organization, operation and administration. The specific remit of AIDS theme research is to help inform the Department about how to meet its policy objectives for HIV/AIDS, which, broadly speaking, are to stem the spread of HIV infection (preventive services),

and to provide the necessary HPSS for those affected (treatment services).

Both prevention and treatment policy objectives have been covered in a research strategy which is based on five questions:

- *What is the need for HIV services — how many and which groups of people require the services?*
- *Are HIV services adequately available and accessible to those who need them?*
- *Are HIV services effective?*
- *What is the cost of providing HIV services?*
- *What are the information, training and support needs of service providers?*

At July 1990, there are fifteen projects underway and thirteen completed, covering the five aspects above, with a total cost of two million pounds over five years. A further fourteen projects are being developed. The *Yearbook* has abstracts of projects underway during calendar year 1989*, but this chapter also mentions some projects which have started during 1990 and some completed during 1988. Each of the AIDS research theme priorities will be considered in turn.

SERVICE NEEDS

Preventive services

Research has been commissioned to define how the HPSS can best be targeted to help individuals avoid acquiring, or passing on, HIV infection. A study by Coxon *et al* (project 5.76, page 111) focuses on male homosexuals, the largest group of HIV-infected people in the UK. This project estimates the stable norms of sexual behaviour in homosexual men, on a representative national basis. It also looks at the use of condoms and other 'safer sex' practices, and whether they continue. A follow-up study by Davies and Coxon began in July 1990 and focuses on male homosexual prostitutes, a high-risk group for acquiring and spreading HIV. It will look at awareness of safer sex practices and patterns of communication between prostitutes, their clients and partners, which influence the use of safer sex. The results should help in the provision of appropriate health education and primary care services for male homosexual prostitutes, their clients and partners.

*Listing numbers and page references are given in brackets, for example: (5.75, page 111).

A further high-risk group — and therefore a priority for preventive services — are injecting drug-users. Some of this group also engage in prostitution as a means of financing their drug habit. A study by Faugier and Klee began in May 1990 to look at the drug-related, sexual and health-care behaviour of male and female drug-using prostitutes. The behaviour of a control group of male and female non-drug-using prostitutes will also be studied.

Treatment services

Research is needed to define the amount and type of health care and social support required by people with HIV infection. Miller *et al* (project 5.75, page 111) are studying hospital service provision for HIV-positive and AIDS patients attending a West London hospital. An assessment is being made of the services used from pre-test counselling through to terminal care. The findings will assist the planning of services and estimation of the resources required to meet future demands. A project by McCann (5.1, page 85; see also the article on page 13) uses the same study population to investigate services provision from the consumer's point of view. It looks at the patients' experience of, and attitudes toward, the care received; how the care was negotiated, the appropriateness of care and patient satisfaction. Robinson *et al* (project 5.72, page 110; and article on page 17) are studying the personal social service needs of HIV and AIDS patients and the response of Social Services Departments (SSDs) to that need.

A heavy burden may fall upon the informal carers — friends, neighbours, relatives — of HIV and AIDS patients; they will have their own needs, particularly for personal social services support. The projects mentioned above by McCann and Robinson both investigate this aspect. Another important area is patient counselling: a short study of patient counselling by Robinson *et al* highlighted the most effective methods of counselling and indicators of which groups are most in need of counselling.

Future research

At present, the largest population group in the UK affected by HIV/AIDS is homosexual and bisexual men. It is anticipated that, in the next few years, heterosexual spread to women will increase and with that, transmission from infected women to the foetus during pregnancy. Future projects will study the service needs of women and children in particular. Counselling requirements from different sectors of the population, particularly those who request HIV testing, is another priority for future study.

SERVICE AVAILABILITY AND ACCESSIBILITY

The groups at risk of HIV infection and those already infected come largely from sectors of the population which may find it harder than others to seek the health care and social support they require. It is imperative that the services provided meet clients' needs and that

they are accessible. Several projects are investigating these aspects.

Organization of local services

Professor Pettigrew *et al* (project 5.77, page 111; and article on page 20) are undertaking a study of the ways in which health authorities have set up HIV/AIDS services. Four health authorities facing different types of HIV challenge are being studied sequentially. In two districts, the HIV/AIDS burden falls on hospital services, and in the other two, the burden is on preventive (health education) services. The results will produce a generic picture of how the challenge of HIV/AIDS has been tackled at health authority level and will guide health authorities still relatively untouched by the epidemic. The project by Robinson *et al* (5.72, page 110) is carrying out a similar analysis of the response of SSDs to the challenge of AIDS, based on a structured national survey. The output of this study should help SSDs to develop their services further.

Delivery of specific services to clients

The role played by needle-sharing among injecting drug-users in the spread of HIV, is reflected in a study of the involvement of community pharmacists in needle and syringe supply and related activities, completed by Glanz (project 5.69, page 110). The results showed that promoting the participation of community pharmacists in the prevention of spread of HIV among IDUs is a viable policy, but that several problems would need to be overcome before it was implemented.

In 'outreach' schemes, health and social care professionals go out to hard-to-reach, at-risk groups (IDUs, prostitutes and the homeless) who have not yet been reached by existing prevention and health services. This may be seen as a direct counter to the problem of poor accessibility of services. A study by Hartnoll, Johnson and Holland (project 5.73, page 111) is investigating a range of HIV outreach services by literature review and survey, studying the Central London Action on Street Health (CLASH) initiative in particular. The study will concentrate on the lessons that could be learnt by future outreach initiatives elsewhere.

Future research on service availability and accessibility

Future research will look at factors affecting the take-up of services, for example nature, staffing, location and opening hours. In particular, what effect do the voluntary sector services have on the take-up of statutory services?

SERVICE EFFECTIVENESS

As well as meeting the needs of the consumer and being accessible, it is obviously important to the patient as well as to the health authority that the services provided are effective. A range of projects is

looking at the effectiveness of several types of service provision:

Preventive services

Needle-sharing is the main risk factor for spread of HIV infection between IDUs. Needle-exchange schemes aim to prevent the spread of infection by counselling and by providing sterile injecting equipment. In 1987, fifteen pilot needle-exchange schemes were set up in England and Scotland with the expectation of changing the attitudes and behaviour of IDUs with respect to drug injecting and sexual practice. Stimson undertook a study to monitor the implementation and impact of these pilot schemes. He found that the syringe-exchange schemes were successful on a number of criteria: for instance, they attracted substantial numbers of clients, many of whom had had little previous contact with drug agencies. The results gave reason for cautious optimism that syringe-exchanges help people who inject drugs to reduce the risk of HIV infection and of transmission to others.

Stimson started a second project in December 1988 on the development of needle-exchange schemes (project 5.74, page 111). This project looks at the effectiveness of the scheme by studying its ability to reach and retain IDUs. Clients of the needle-exchange scheme will be compared with IDUs who have not used the scheme, to examine how scheme-related factors influence short and long-term changes in HIV-risk-related behaviour. The organization, development and delivery of the needle-exchange service will also be examined.

The project by Hartnoll, Johnson and Holland (project 5.73, page 111) mentioned above will look at the effectiveness of the CLASH outreach project in Central London in hard-to-reach, at-risk groups. A literature review completed by Glanz looked at the treatment provided for IDUs with the primary intention of weaning them off addictive drugs. In particular, the factors affecting how long an IDU remained on treatment and the influence of treatment on the HIV-risk-related behaviour of drug misusers were studied.

Effective coordination and delivery of services

A project by Bebbington and Goldie (entry 5.7, page 89/90) is evaluating the Landmark Centre, which opened in June 1989. This is an initiative by Lambeth AIDS Action in South London to provide community support to people with AIDS and HIV infection. The Centre is unusual in that a wide range of facilities will be provided by volunteers, supported by eight full-time staff. The evaluation will look at how the Landmark Centre influences requirement for, and provision of, services from other agencies. Users of the Centre will be followed up to assess the amount of support gained. The Landmark Centre is a pioneering project in the UK and its evaluation will both help the Centre to develop and to provide a model for future initiatives.

The Northern Region Community Support Centre

differs from the Landmark Centre in that it is an extension of statutory community-based services to support people with HIV-related illness. Bond began in June 1989 (entry 5.14, page 94/95) to undertake an analytical description of the Northern Centre's objectives and the extent to which these are met. Again, this will provide useful information for other health authorities contemplating similar schemes.

The population group most affected by HIV in the UK, homosexual and bisexual men, has a relatively high incidence of sexually-transmitted diseases. This leads to their higher attendance rate than the general population at Genito-Urinary Medicine (GUM) clinics. The onset of the HIV epidemic, also spread predominantly sexually, has increased the numbers of patients seen in GUM clinics; a project by Allen is investigating this increased workload. The roles and responsibilities of different types of staff will also be studied with a view to making recommendations on how these clinics might improve their efficiency and cost-effectiveness.

Future work on effectiveness of services

At present, most HIV/AIDS cases are treated in a few areas of high prevalence, for example, London and Edinburgh. The hospitals providing treatment are offering a specialist service for a condition which is uncommon elsewhere. As the epidemic spreads, HIV/AIDS patients will be treated in more places which have less experience of managing the disease. Future studies will therefore compare the management of HIV/AIDS patients in different settings and compare outcomes; new measures of quality and care may also need to be devised for this fatal disease. The effect of developments in treatment – for example, effective drugs for delaying disease progression – on service needs and organization will also require study.

THE COST OF HIV/AIDS SERVICE PROVISION

Statutory HIV/AIDS services are provided by both health authorities (health care) and local authorities (personal social services). DH-funded studies have looked at costs in both of these areas.

Local authority costs

Bebbington (entry 5.7, page 89/90; and article on page 23) looked at the cost of social service provision, taking into account the predicted number of cases, existing data on the costs of each service and the range of services provided or planned. This study estimated the likely revenue costs of local authority services for HIV/AIDS in 1988/89 and 1989/90, and summarized the policy response of ten local authorities. The final report has been used by the Department in calculating its bid to Treasury.

The project by Robinson (project 5.72, page 110; and see above) also looks at the cost of social service provision, amongst other things. Part of the evaluation of the Landmark Centre (see entry 5.7, page 89/90), also mentioned above, involves costing the

community support initiative, which brings together voluntary and paid staff.

Health authority costs

Rees undertook a study looking at the cost to three health authorities of providing HIV/AIDS services (project 5.70, page 110; article on page 26). Using a different approach, he is now following a cohort of 120 London patients diagnosed as having AIDS in 1985 to assess the costs of the services they used. The project by Miller *et al* (project 5.75, page 111; and above) is looking at the cost of hospital service provision by Parkside DHA — part of the North West Thames Regional Health Authority — for cohorts of HIV positive and AIDS patients.

Future costing studies

Future studies will focus on the factors affecting costs to local and health authorities. Studies of the cost-effectiveness of different strategies for prevention and treatment will also be needed.

SERVICE PROVIDERS

To care for HIV/AIDS patients, service providers need to be knowledgeable about HIV infection and AIDS, but also need to be able to cope with the demands of patients suffering from a distressing disease. DH-funded research has looked at both of these aspects.

Freeling and Sibbald carried out a study in 1987 of knowledge, attitudes and behaviour regarding HIV/AIDS in GPs in the South West Thames Region. They went on to study general practice vocational trainees and their trainers in seven regions of England and Scotland in 1989 (project 5.71, page 110; article on page 29). A postal survey of knowledge and attitudes supplemented by telephone interviews was carried out with the aim of identifying ways of improving HIV/AIDS teaching in vocational training.

Foy and Gallagher (see 5.14, page 94/95 and article, page 31) carried out a survey of 20 per cent of all general practice principals in England and Wales, in Summer 1988. Their findings on knowledge, attitudes and behaviour were similar to those of Freeling and Sibbald. They also estimated the HIV-related consultation rate in general practice at 6.5 consultations per 1,000 population per year, on average, nationwide.

A similar study, also at the Health Care Research Unit, University of Newcastle (5.14, page 94/95), was undertaken simultaneously by Senga Bond. A 1 in 5 sample (5,243) of community nursing staff in England was invited to participate in a postal survey of knowledge, attitudes and behaviour towards HIV/AIDS. As with the GPs, community nurses were concerned about their lack of knowledge and lacked confidence to provide health education and counselling. The study concluded that community nurses needed help in making links between the knowledge they already possessed and its application to HIV/AIDS.

The Department funded an educational initiative on HIV/AIDS for community nurses in 1988. This

consisted of a two-day residential workshop in each English health region, organized by senior nurses from the Department of Health, the English National Board for Nursing, Midwifery and Health Visiting, Riverside Health Authority (which has much HIV/AIDS experience) and two representatives from the host Region. The aim of the workshop was for senior nurse managers to develop certain skills at the end of two days, and, in the longer term, to facilitate a flow of knowledge, skills and attitudes to nursing staff in their respective districts. Mrs Barbara Roberts (then Robottom) was commissioned to evaluate the workshops as a method of promoting information and education on HIV/AIDS for nurses. A follow-up, after six months, of those who attended the workshop investigated whether their ideas on policy, practice and education within their districts had been carried out.

The four projects described above, on HIV/AIDS and primary care staff, were brought together in a seminar hosted by the Department and entitled *HIV: the training needs of primary health care staff*, held on 27 February 1990. A multidisciplinary audience of around sixty heard presentations of each project and participated in a discussion of the implications for training.

A study by Akinsanya (project 5.68, page 109) is looking at the knowledge and activities of hospital nurses in relation to HIV/AIDS. It is being carried out in three selected English health authorities with sizeable HIV/AIDS patient loads together with a control health authority with very few HIV-positive patients. It will provide a profile of the attitudinal and managerial problems and identify areas for development.

Future studies on service providers will be needed which concentrate on how formal and informal carers are coping with the demands of HIV/AIDS patients in terms of their availability, turnover, willingness to treat patients and 'burn-out'.

CONCLUSION

DH-funded AIDS research has grown from nothing in 1984 to a reasonably well-balanced portfolio. It has been partly stimulated by spontaneous enquiries from researchers which have coincided with policy division's research requirements. In other cases, policy divisions have defined their research needs, and researchers have been invited by the Department to tender. A strategy for DH-funded AIDS research has been developed which is reflected in the pattern of studies commissioned, and in future, most contracts will result from the Department inviting researchers to tender for specific projects in line with the strategy. However, the Department will continue to consider spontaneous enquiries in the interests of maintaining a flexible programme adapted to changing priorities.

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The Contribution of Research to Policy Development in HIV/AIDS

The emergence of AIDS in the early 1980s and the identification of the causative virus HIV in 1983 have provided health and social care systems throughout the world with a major challenge. A wide range of responses were needed:

- educational activities to inform people of the ways in which HIV can be transmitted, and to seek to persuade and assist them to avoid behaviour through which the virus could be transmitted;
- provision of counselling, care and treatment to those infected with the virus;
- safeguarding blood, organ and blood product supplies through self-deferral of donors who might have been at risk of HIV infection, testing of donations for HIV antibodies and, where possible, treatment of products to inactivate the virus.

Enormous progress has been made in understanding the way in which HIV is transmitted and attacks the immune system. Treatments have been developed which slow the effects of the virus, and prevent or reduce opportunistic infections in people with HIV. But there is no prospect in the foreseeable future of a cure, and a vaccine may not be available within the next ten years.

AIDS is a condition which raises many fears and prejudices, partly because HIV is chiefly transmitted sexually, currently affecting homosexual men more than others in the UK, or has been spread by sharing injecting equipment during illicit drug use. Public debate has been made more intense by the fact that AIDS is fatal and kills mostly young people. These factors have had a number of implications:

- it has been necessary for services to provide a very high degree of confidentiality to clients and patients;
- staff have needed training to overcome unfounded fears that they will become infected; to help them to come to terms with their own feelings about sexuality, drug misuse and death; and to ensure they are aware of the hygiene and confidentiality standards they need to apply;
- services have had to develop against a background of uncertainty about the natural history of the infection, rapidly changing treatment and management patterns, and uncertainty about the number of people infected and likely to fall ill in the near future.

From the beginning, the Department has sought to ensure that statutory health and personal social services agencies have been equipped to respond to the challenge presented by HIV through guidance on infection control and on the development of services and prevention activities, and through earmarked finance. The Department has also recognized the important role of voluntary agencies and has provided financial support for both care activities and projects focusing on prevention.

Significant amounts of public money are now being spent in response to HIV/AIDS. In 1990/91, health authorities are receiving £129m. earmarked for prevention, care and treatment of HIV disease. Local authority social services departments are receiving £9.8m. as a 70 per cent support grant against estimated expenditure of £14m. The Health Education Authority (HEA) is receiving £10m. for its AIDS education programme, and voluntary bodies are receiving central grants of £1.8m. for their work, in addition to support they receive for local activities from health and social services authorities, and charitable giving.

Research has an important part to play in informing the Department's response to HIV and AIDS. The Medical Research Council's AIDS Directed Programme on vaccines and anti-viral drugs, and its Strategic Programme are likely to have implications for health services in due course, but these lie outside the scope of this article. The HIV epidemiology programme, which the Department is supporting through grants to the MRC, is also of great importance and should provide more reliable estimates of the likely future spread of HIV and AIDS. This kind of information is essential for resource planning and in deciding how best to target educational and other preventive activities. The programme of anonymized studies of HIV prevalence, which started in January 1990, currently covering a sample of antenatal patients and attenders at Genito-Urinary Medicine (GUM) and drug clinics, and which will be expanded to include certain newborn babies and general hospital patients, should greatly improve information about spread of HIV. This information will be used for local and national resource planning.

The Department has prepared a statement setting out the areas in which information is required and in which it expects research to help inform decisions which must be taken to achieve policy objectives

relating to the organization and funding of services. The following main information requirements have been identified:

- Service needs
 - characteristics of groups at risk and their needs for services to limit the spread of HIV infection;
 - needs of those presenting for counselling;
 - health care and social support needs of HIV-infected people;
 - impact of housing needs of people with HIV on other services;
 - support needs of carers.
- Service availability and access
 - factors affecting the establishment of HIV prevention, care and treatment services;
 - factors affecting their take-up;
 - effectiveness of outreach and domiciliary services;
 - role of the voluntary sector in facilitating access.
- Service effectiveness
 - organization, coordination and delivery of local services;
 - impact of preventive services in influencing behaviour;
 - quality of care;
 - effect of different models of service on outcomes;
 - interaction of prevention and treatment initiatives.
- Service costs
 - costs for health and personal social services of caring for people with HIV;
 - reasons for variations in costs, including impact of volunteer services;
 - cost-effectiveness of prevention and treatment strategies.
- Service providers
 - how knowledgeable staff are about HIV;
 - reactions of staff to HIV (eg turnover, willingness to work in this field, burn-out);
 - training and education needs of staff.

Research has been commissioned under all of the main headings above and under most of the sub-headings. As the reports of projects become available, the findings will feed into policy development work in the Department. The Department will also be looking for opportunities to publicize findings to agencies which commission or provide services. Approaches to be used to achieve this include organizing seminars to discuss project results, and encouraging authors to give papers at conferences and to submit articles about their work to specialist and professional journals.

There are thirteen completed projects on the health and personal social services aspects of HIV; several have already been of direct use to the Department:

- Stimson's project on *Monitoring Injecting Equipment Exchange Schemes* has confirmed that such schemes have an important role to play in preventing the

spread of HIV from and amongst drug injectors, but has also shown that such schemes provide part, but not the whole of the necessary response. It has also provided important information that should be taken into account when planning and developing services. This has been promulgated to the NHS and other field agencies.

- On a more modest scale, Robottom's evaluation of workshops on AIDS for community nurse managers showed what further steps needed to be taken in this field.
- Costing studies, by Bebbington (see entry 5.7, page 89/90; and article on page 23) for local authorities, and by Rees for the NHS (project 5.70, page 110; and article on page 26), have been important in determining the expenditure which HIV and AIDS is causing for statutory bodies, and in securing the earmarked funding mentioned above.
- The studies by Freeling *et al* (see project 5.71, page 110 and article, page 29) and by Foy and Gallagher (5.14, page 94/95; article — page 31) on HIV and general practice, and by Bond *et al* (entry 5.14, page 94/95 on HIV and community nurses have identified training and staff support needs. These are important in relation to the Department's policy objective that care for people with HIV disease should be provided in their own homes wherever this is in their best interests.
- Glanz's survey (5.69, page 110) of the role of the high street pharmacy in the prevention of AIDS among drug-users gives important information relating to gaining access to those drug-users who may be termed 'higher risk'. It gives an indication that it might be possible to build on the partial success already achieved by needle-exchange schemes and the development of outreach work.

Other projects which are not yet completed have been structured so that interim results are fed back to the Department and provider agencies. For example, the study *Development of AIDS Services by DHAs: The Organizational Response*, by Pettigrew, Bennett and Ferlie (see project 5.77, page 111; and article — page 20), is designed to give feedback to each of the authorities in which fieldwork is carried out, as well as to produce a final report.

Finally, the importance of the research sponsored by the Health Education Authority should be acknowledged. A tracking study of public attitudes and knowledge about HIV and AIDS has been carried out, initially for the Department and since late 1987 for the HEA, by the British Market Research Bureau. The results play a crucial part in determining HIV/AIDS health education policies, and are published. Numerous specific research projects have also been commissioned into particular areas in which the HEA has to make decisions on programme development.

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Kathryn McCann and Emma Wadsworth
Entry 5.1, page 85

Living with AIDS: the Experience of Care

INTRODUCTION

In a recent study 265 gay men, positive for the HIV virus, were interviewed about their experiences of, and attitudes towards, the care they received and about the social context in which that care took place. Respondents, who were all attending a single London teaching hospital, were recruited between November 1988 and June 1989. Formal and lay carers identified by the person with HIV infection or AIDS were also interviewed about their opinions and experiences of the services. The aims of the study were to chronicle the relationship between care in the community, and in the hospital, as well as to examine the appropriateness of care and to establish levels of satisfaction.

THE INTERVIEWS

People with HIV infection or AIDS were interviewed on two occasions: when they were first recruited to the study and again approximately ten months later. On the first occasion, they were asked about their use, views and experiences of health, social and voluntary agencies; any social changes brought about by their positive HIV status; and about housing, finance and social support. The second interview updated details of service use and mapped any changes in the use of services and views expressed about them. Thirty-nine per cent did not have a repeat interview: this was largely explained by illness, death or change of address.

Informal carers — that is, those giving regular, unpaid support or care to someone in the study group, who were mainly partners (46 per cent), friends (41 per cent) and parents (4 per cent) — had a first interview, with the possibility of a second. The first interview covered their views and experiences of the services used by the person they cared for. In addition, carers were asked what they did to help, and the impact caring had on their own life, either physically and/or emotionally. Repeat interviews take place, where appropriate, after the death of the person with HIV infection or AIDS, when issues of terminal care, bereavement counselling and any changes in circumstances brought about by the person's death are discussed. These second interviews will not be completed until early in 1991.

A third set of interviews was carried out with formal carers, who were nominated as the people giving the most practical help or who had been the most supportive. These were mainly clinic doctors, nurses from the Home Support Team (HST) and some community-based staff, including GPs and therapists. Again, two interview schedules were used: the first asked about their perceptions of the services available to people with HIV infection, and about any structural problems they encountered in their day-to-day work. The second schedule covered what they had done for the individual who had nominated them and their opinions about the care he had received.

CHARACTERISTICS OF THE STUDY GROUP

The study group was recruited through the Genito-Urinary Medicine (GUM) clinic and the designated wards at a London teaching hospital. Over half of all HIV-positive gay men registered at the hospital were contacted. Excluding those who did not actually attend the clinic during the recruitment period, we succeeded in contacting approximately 80 per cent. Of the group interviewed, 66 per cent were working, the majority full-time; 47 per cent fell into social classes I and II and were therefore professionals; 45 per cent owned their own accommodation and 40 per cent lived alone. The whole range of HIV disease was represented within the group, from HIV-positive and asymptomatic, to AIDS.

SERVICES USED

The men in the study group had had contact with a wide variety of health, social and voluntary services.

Primary health care

Eighty-seven per cent of the informants were registered with a GP; however, of these, only 15 per cent had seen him or her within the last six months. Of the total registered with a GP, although 55 per cent said that the doctor knew about their HIV status, only a third of these had consulted him or her about an HIV-related matter. Where they had seen their GP, the majority had consulted only once, and 90 per cent had been for prescriptions only. Sixty-two per cent of those who had used their GP felt that he or she had done all they could to help. Amongst the informants there

seemed to be an underuse of general practice. This appeared at two levels: firstly, a relatively large proportion (13 per cent) were not registered with a GP in the NHS at all. Cartwright and Anderson¹, in a study of use of GPs by a random sample of people, found a much lower rate of non-registration, that is 2 per cent. Secondly, informants appeared reluctant to use a GP, even where they were registered. The following comments illustrate the reasons for this. Firstly, there was a lack of confidence in GPs' knowledge of HIV infection:

'I have no confidence in him. Unless it becomes absolutely necessary, I won't tell him anything related to HIV.'

Secondly, there were fears about the maintenance of confidentiality:

'It [HIV diagnosis] would be on my notes and open to reading by all the clerical people.'

Similar reasons for reluctance were found by Mansfield and Singh² in a study about the use of general practice by HIV-positive gay men. A further element was that informants expressed a preference for out-patient clinics for their routine medical advice:

'Because it's easier to go to the hospital. They fulfil that [the GP's] function.'

Of the other primary health care professionals, only eight people had had contact with a district nurse. One individual reported contact with another kind of community nurse.

Out-patient services

The majority of the people in the study group were attending either an HIV clinic within the Genito-Urinary medicine (GUM) clinic (54 per cent) or a special HIV immunology clinic at the hospital (38 per cent). Frequency of attendance varied, with a quarter attending at least once a fortnight, and a further 32 per cent at least once a month. As can be seen from Table 2.1, the time spent at the hospital for out-patient visits varied enormously. This time covered not only seeing the doctor, but also waiting time, and seeing other health care staff.

Approximately three-quarters (72 per cent) felt that the doctors spent enough time with them during their actual consultation, whereas 19 per cent felt that the doctors were hurried. Appraisal of out-patients was generally favourable. Fifty-four per cent of the study group felt that they were given a lot of reassurance and support by outpatients' staff, and 73 per cent felt that the staff were very kind and understanding.

TABLE 2.1: Time spent at hospital for out-patient visits

Time	%
up to 1 hour	2
1 – 2 hours	21
2 – 3 hours	36
3 – 4 hours	25
4 – 5 hours	5
5 or more hours	11
n = 255*	100

* a small number of people did not answer this question or did not complete the interview because of ill-health.

Private general practitioners or clinics

Fourteen per cent of respondents had had contact with a private GP or clinic, and of these 30 per cent had only attended once, either for an HIV test (22 per cent) or for general medical care (22 per cent). The remainder had gone for a variety of reasons, including psychiatric consultations, nutritional advice or specific treatment not available in the NHS. A third of those not registered with a GP in the NHS had attended a private clinic on at least one occasion.

Social service provision

Of the whole group, 22 per cent (58) had been in touch with a social worker; 40 per cent had seen him or her only once, and half said that the social worker had contacted other services on their behalf. Sixty per cent of those who had seen a social worker found him or her very helpful, and 72 per cent said that he or she was very kind.

Only one other local-authority-based social service, namely the home help service, was mentioned by respondents. Five per cent (12) had been visited by a home help and of these, a third found him or her very helpful.

The Home Support Team

A clinic-based specialist Home Support Team (HST) is available to HIV and AIDS patients attending the hospital. The team, established in 1987, was developed along similar lines to existing cancer support teams and was intended to coordinate hospital and community services, in particular to allow patients to be cared for at home.

Predominantly, the work of the HST was seen in terms of spending time talking (62 per cent), giving advice (58 per cent) or reassurance and support (31 per cent). Only 16 per cent perceived the team's role as being purely practical. Table 2.2 shows that just under half said that the team had contacted other services on their behalf (for example, finding a sympathetic GP or dentist) — far more than mentioned traditional nursing activities.

In terms of a general rating, people were happy with their contact with the HST, 49 per cent describing them as excellent and 37 per cent good.

TABLE 2.2: What the HST did to help*

Function	%
Injections	11
Dressings	8
Medicine	9
Massage/exercise	3
Temperature measurement	12
Taking blood	9
Arranging meals/transport	4
Contact with other services	37
Giving advice	58
Giving reassurance and support	34
Bereavement support	3

* 119 people answered this question, and more than one response was possible, so percentages total more than 100 per cent.

Voluntary organizations and other professionals

Study subjects had been involved with a number of other professionals, as well as voluntary organizations. Fifty per cent of respondents had consulted a dentist, 49 per cent a psychologist, 27 per cent a dietician, 19 per cent a solicitor, 4 per cent a psychiatrist and 3 per cent an occupational therapist. A few had also seen other professionals, such as homeopaths and psychotherapists. Seventy-five per cent of these professionals were seen through the NHS, 16 per cent were seen privately, and 9 per cent were listed as ‘other’ (for example, largely as a consequence of participating in other research projects). Mostly, professionals were seen as being very helpful (56 per cent) or fairly helpful (28 per cent).

Over two-thirds of informants had had some contact with one or more voluntary organizations: 48 per cent had contacted the Terrence Higgins Trust, 39 per cent Body Positive, 25 per cent Frontliners, 19 per cent London Lighthouse and 6 per cent Immunity. Of these, three-quarters had received help from them; for 14 per cent, this consisted of a member of the organization visiting them at home and giving them regular support which was generally seen as being very helpful (73 per cent). Of the remaining people who had had contact with the voluntary agencies, the majority had made a single contact, which suggests that such organizations were frequently used on a one-off basis for support, information, advice (particularly legal and financial) or for courses and group meetings.

COMPARISON OF SATISFACTION WITH SERVICES

Informants were in contact with a wide variety of carers from both the statutory and non-statutory services. A comparison of the different services, however, indicates that levels of satisfaction varied considerably.

Table 2.3 shows that study subjects had more favourable comments about the HST and out-patients than about GPs and private clinics. This was a significant difference and corresponded with a higher use of the HST and out-patients services.

TABLE 2.3: People’s assessment of quality of care given by GPs, and staff in out-patients, private clinics, and by the HST

	GPs %	Out-patients %	Private Clinics %	HST %
Very kind and understanding	49	73	43	78
Fairly kind and understanding	34	20	31	18
Not kind and understanding	2	1	6	4
Other	15	6	20	
Numbers using the service (100%)	42	262	35	119

Table 2.4 shows that variability of satisfaction using a general rating was less marked. People were still more likely to rate the care given by hospital out-patients and the HST as excellent or very good, than that given by GPs. Again, this was a significant difference.

TABLE 2.4: Ratings of satisfaction with care provided by GPs, out-patients and the HST

	GPs %	Out-patients %	HST %
Excellent	40	48	49
Very good	30	38	37
Fairly good	19	12	8
Poor	11	2	6
Numbers using the service (100%)	42	262	119

SUMMARY

Our data show that the study group were using a wide variety of health, social and voluntary services. It seems, however, that the hospital-based services were more frequently used than the community-based ones. This is clear from the underuse of GPs and the parallel use of out-patients for routine medical advice, not just that related to HIV. It is also indicated by the high level of contact with the HST, as compared to community-based nursing services. The HST was

more often reported as having a role in advice-giving, offering reassurance and support, and facilitating contact with other services, such as GPs and dentists, than they were with more traditional nursing care. Voluntary agencies also provided concerted support for a small group of people, but were more frequently used for advice and emotional support about specific issues. Significantly higher levels of satisfaction were expressed about hospital-based services than about the community-based ones, although the numbers using the latter were small.

References

- ¹ Cartwright A, Anderson R, *General practice revisited. A second study of patients and their doctors*, London, Tavistock Publications (1981)
- ² Mansfield S J, Singh S, 'The GP and human immunodeficiency virus infections: an insight into patients' attitudes', *Journal of the Royal College of General Practitioners*, **39** (1989) 104-105

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David Robinson, Alan Maynard and Gilbert Smith
Project 5.72, page 110

Investigating HIV/AIDS and Social Care

Much of the research effort in relation to HIV/AIDS has been devoted, so far, to biomedical investigation into areas such as the nature of the virus and to epidemiological investigation into its prevalence and pattern of spread. Such research has been coupled with the development of clinical and counselling programmes to treat and support those with HIV/AIDS, and of health education campaigns to encourage appropriate sexual behaviour in the population as a whole. The focus of this work has been on primary and secondary health care provided within the NHS.

As the number of those with HIV/AIDS increases, an equally important concern is to understand the pattern and range of social care needs and how best these can be met. This article reports progress on a two-year project, funded jointly by the Department of Health (DH) and the Scottish Education Department (SED), and based at the Universities of Hull and York, which focuses on a number of key social care issues. These include the range of HIV/AIDS-generated needs for formal and informal social care; the nature of the delivery, management and coordination of that care; the development by Social Services Departments (SSDs) in England and Wales and Social Work Departments (SWDs) in Scotland of their patterns of provision; and the direct and indirect costs of social care for those with HIV/AIDS. These issues are being investigated in three complementary studies:

- a survey, in five local authority areas, of those with HIV/AIDS, to show what SSD–SWD, private, voluntary and informal social care is used and desired;
- a study of SSD–SWDs in the same five localities to detail their patterns of social care provision and future plans;
- a national survey to show in broad outline the range of SSD–SWD social care provision in England, Wales and Scotland, together with plans for development.

THE SOCIAL CARE NEEDS OF THOSE WITH HIV/AIDS

The survey in five areas is designed to identify the pattern of social care desired and received by those with HIV/AIDS; the study also identifies the support and assistance needed by their informal carers. The basic information is coming from personal interviews

with 180 respondents resident within the five study localities: Hammersmith and Fulham; Westminster; Kensington and Chelsea; Manchester; and Lothian. The research strategy combines a cross-sectional survey and the re-interview of fifty people representing the full spectrum of HIV/AIDS. Within each locality there is variation, but overall a full range of experience and conditions is being sought. The re-interviews provide some indication of the nature and speed of change in the patterns of desire for social care.

For the cross-sectional survey, we are using a mainly structured questionnaire, but there is provision for some qualitative exploration. Respondents are asked about the range of needs they experience for different elements of social care, the extent to which these are being met from SSD–SWDs, voluntary organizations, private agencies and informal carers, and their evaluation of what they receive. 'Quality of life' measures are also used. Additionally, respondents are asked to complete a 'budget diary' which records, for the previous week, activities and events, finance and personal resources called upon, and the extent to which these were HIV/AIDS related.

THE DEVELOPMENT OF SSD–SWD PROVISION IN FIVE LOCALITIES

In the study of service provision we are focusing on several general organizational issues in relation to SSD–SWD activities. Of particular concern are:

- management policy in the light of potentially rapidly growing demand and the changing environment;
- adaptability of practitioners to new service requirements;
- response to new demands in the variable contexts of residential and field social work;
- policy and practice on inter-agency cooperation.

The main emphasis, however, is on the development by SSD–SWDs of specific packages of social care for those with HIV/AIDS. These packages involve coverage of housing, finance, physical and emotional needs, and include the provision of meals on wheels, 'dedicated' social workers, home help services, occupational therapy, telephones, day centres, transport, incontinence services, night sitting, collection of clinical waste, counselling and support, home loans,

equipment, hospital discharge coordination, and hostel-hospice provision.

Key informants in each of the five SSD-SWDs have been interviewed about currently available statutory, voluntary and private services, about management and coordination arrangements and about plans for the future. These interviews have been supplemented by an analysis of policy documents, discussions with senior practitioners and social workers at the basic levels of professional practice, attendance at meetings and assembling case studies. In addition, postal surveys have been conducted to ascertain the views of specific occupational groups, such as social work team leaders, the heads of hospital social work teams, senior occupational therapists and home-care managers. Key informants from other statutory services and voluntary agencies were identified as our knowledge and experience of each locality developed, and their views on social care provision, management and coordination arrangements are being assembled. Information has also been gained from detailed questionnaires completed by 79 voluntary organizations.

The study is identifying the pattern and range of existing SSD-SWD services. In conjunction with material from the study of service requirements, this will enable us to make some assessment of the match between provision and demand. This may vary at different and key stages in the HIV/AIDS career and we shall be able to comment on that. This study will also provide evidence relating to certain HIV/AIDS-specific organizational issues, such as:

- HIV/AIDS coordinators
- HIV/AIDS management groups
- internal planning groups
- joint planning
- prevention
- monitoring and evaluation
- training and education

A SURVEY OF ALL SSD-SWDs IN ENGLAND, WALES AND SCOTLAND

The extent to which SSD-SWD policy and practice in the five study localities is generally applicable is also being investigated, in a survey of all SSDs in England and Wales, and all SWDs in Scotland. This survey is designed to identify:

- current SSD-SWD provision, and the nature of coordination and of collaboration with other agencies — both statutory and non-statutory;
- planned SSD-SWD provision, either in response to, or in anticipation of, local demand;
- potential SSD-SWD provision which would be required in order to accommodate the full range of social care desired by those with HIV/AIDS and their informal carers;
- the staff, premises, training, and equipment needed to deliver the current, planned or potential provision.

As a first stage of this study, 128 SSD-SWDs (not including the five study localities) were circulated with a request for policy and planning documents. A total of 92 replies were received, and this substantial amount of information is currently being analysed. It will yield data on:

- training
- information to employees
- information to the public
- service guidelines (eg fieldwork, residential care, day care, domiciliary support)
- confidentiality
- funding

A structured questionnaire was also sent to all 128 SSD-SWDs, with the exception of the five study localities. We identified in each SSD-SWD a key respondent to receive the questionnaire, collate information, and liaise with the project. Visits to some SSD-SWDs have been necessary to gather additional data, to assist with the completion of the questionnaire and to negotiate access.

Where HIV incidence is known or assumed to be high, departments have undertaken considerable planning and have initiated a number of HIV-specific responses to demands for social care. Where incidence is known or assumed to be comparatively low, some departments have developed policies and services in anticipation of future demand, while others feel there is little need for such a response until the demand is expressed.

THE ECONOMIC DIMENSION

A major theme running through the entire project is the concern with the resource consequences of HIV/AIDS-related social care. The economic component of the project therefore aims to:

- estimate the cost of existing SSD-SWD and non-statutory social care provision for those with HIV/AIDS and their informal carers; and
- estimate the cost of various packages of social care, which are designed by those with HIV/AIDS and their informal carers, or considered desirable by those who plan and provide formal services.

Data are being assembled through interviews with key SSD-SWD personnel and local authority finance staff, and from resource documents, which will enable us to identify the resource implications of both formal and informal care for the numbers of people having HIV/AIDS. They will also allow us to estimate the cost, in the five study localities, of the evolving HIV/AIDS strategies of SSD-SWDs. Questions have been included in the national survey of all SSD-SWDs to allow us to assess the average and marginal costs of current inputs into specialist and generic HIV/AIDS-related services and programmes. Estimates will be produced of the costs of planned or potential SSD-SWD activity.

A model of SSD-SWD social care supply is being developed with component costs of:

- management and coordination
- staff training

- health education and prevention
- housing and accommodation
- care and support, and
- monitoring and evaluation

SUMMARY

In this article we have outlined progress on a DH–SED funded study comprising:

- a cross-sectional survey and panel study in five study localities which will indicate what SSD–SWD, private, and voluntary and informal care is used and what is desired;
- a study of the SSD–SWDs in the same five localities which will detail their pattern of provision and future plans and possibilities;
- the national survey which will outline the range of SSD–SWD provision in England, Wales and Scotland, together with plans for development.

Our aim is to investigate the nature, extent and cost of existing and possible future packages of social care. Alternative planning scenarios will be drawn up and estimates made of the cost of their adoption nationally. A series of project reports will be presented to our funders during 1990 and associated publications dealing with a wide range of service, organizational, methodological and policy issues will follow.

The three authors are co-directors of the project: David Robinson is Professor of Health Studies at the University of Hull; Alan Maynard is Professor of Economics at the University of York; Gilbert Smith is Professor of Social Administration at the University of Hull.

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Developing Services for HIV/AIDS: Organizational Learning in District Health Authorities

INTRODUCTION

HIV/AIDS — An organizational perspective

The DH-funded research on which this paper is based — *The Development of AIDS services by District Health Authorities (DHAs): the Organizational Response* — is a two-and-a-half-year project which began in January 1989^{1,2}. The aim of the research is to provide an organizational analysis of the local response to HIV/AIDS in four District Health Authorities (DHAs); it builds on and extends two studies of the development of HIV/AIDS services in Parkside and Bloomsbury DHAs³.

The management response to HIV/AIDS reflects the special problems of organizational learning under the conditions of crisis, uncertainty, and continuing change. The lack of basic knowledge and experience, the uncharted epidemiology of the disease, rapid changes in treatment models, and the White Paper *Working for Patients* all contributed to this ever changing background. In this article, we use empirical data to consider some processes and outcomes of the learning which has taken place in relation to HIV/AIDS within DHAs, and to look at some implications of what has been learned for developing and managing services in the 1990s.

DATABASE AND METHODS

The method used is comparative, longitudinal, individual case studies in four DHAs; three case studies have been completed. Since no one DHA can be considered 'typical', the findings of one cannot be generalized. However case studies do capture the richness of context and process, and, in considering the results of several cases, patterns begin to emerge. The case studies comprised different types of data collection, analysis of archival material, formal and informal on-site observation, and interviews with key personnel.

LEARNING TO DEAL WITH HIV/AIDS

Learning can be defined as a relatively permanent change in behaviour occurring as a result of experience, and organizational learning can be said to occur at three levels:

- the individual
- the group
- the whole organization

Shared understanding can occasionally be achieved simultaneously by large numbers of people — for example, during a natural disaster. Normally, however, a collective perception develops through some individuals emerging as early learners. That learning may then diffuse over time, firstly to immediate groups and networks, and in turn to the larger organization of which they are a part.

In general, individuals are motivated to learn by the prospect of external or internal reward. But learning may also occur through exposure to new influences, and this process may be helped by the organizational context. For example, individuals may be *enabled* to pursue their personal interests, may be *rewarded* for learning about an issue, or may be *exposed*, either deliberately or unintentionally, to a wide range of environmental influences.

Our case-study material provides examples of all these. Individual professional autonomy has enabled doctors from a number of specialties, including Immunology, Genito-Urinary Medicine (GUM) — that is, sexually-transmitted diseases, Infectious Diseases, Haematology and Public Health Medicine, to pursue internally-generated interest in HIV/AIDS. The term 'product champion' has been used to describe these key people, who have emerged as an important focus for service development. The prospect of rewards in the form of resources has prompted even those with no initial interest to learn about the issue in order to make credible bids for extra staff, or new equipment. Environmental cues have also influenced learning. Yellow biological hazard stickers in hospitals have taken on new significance with the advent of HIV/AIDS, and staff have learned to take extra safety precautions. Office walls covered in explicit posters have assisted people to learn about, and become familiar with, the social and cultural aspects of HIV/AIDS.

Experiential, formal and informal learning

Much early learning within DHAs was *experiential*: clinicians learned from experience the combinations of drugs best suited to unusual infections, and technicians learned to use new HIV tests by practising laboratory techniques. However, once HIV/AIDS was

recognized as a policy issue, there was an emphasis on formal training. Staff attended lectures and seminars on clinical aspects of the syndrome and on new techniques of infection control and patient care. Nevertheless, formal training was not always appropriate: new skills were needed, but old ones were not necessarily obsolete. Many people already had some basic counselling skills, but emphasizing the need for formal counselling training tended to obscure the possibility of a simple update of techniques.

There was also a need for 'unlearning' of traditional attitudes and values. Patients were sometimes as well-informed as their doctors and the old 'doctor knows best' approach has proved difficult to sustain. In addition, with HIV affecting a wide range of bodily functions, clinicians have had to learn to work across traditionally separate specialities and with external organizations such as social services departments and the voluntary sector.

A formal approach to learning about HIV/AIDS may also offer little help in dealing with deep-seated anxieties or other feelings. As a fatal illness, associated with issues such as homosexuality and drug addiction, AIDS is not a neutral issue, and attitudes are slow to change. Early initiatives, for example, attempted to calm fears of health care staff about the risk of infection by providing factual information about the virus, modes of spread, and methods of protection, but there are still many examples of staff at all levels acting with inappropriate caution. Formal training programmes have of course been useful, but creating a climate in which HIV/AIDS patients would be treated in a sensitive and compassionate way, and in which messages about prevention could be assimilated, involved changing both attitudes and behaviour and required a different approach.

Much learning in organizations is informal. People learn all the time from their environments, and through mechanisms such as posters, postcards or equipment carrying slogans. Conscious attempts at image creation – for example, by inviting Royalty to open new HIV/AIDS facilities – may also increase awareness. At a less dramatic, day-to-day level, informal learning has taken place through the exchange of views and information in such settings as ward meetings and joint committees.

Intentional and unintentional learning

Most of the formal and informal learning considered so far can be seen as *intentional*, deliberately engineered to change attitudes and behaviour towards a desired outcome. However, in every intentional learning situation there is potential for *unintentional* learning. For example, high profile media campaigns on HIV/AIDS may be effective at one level. Most people remember the 'Gravestones and the Icebergs' TV commercials, but both have been criticized for unintentionally making people so frightened of AIDS that they blocked out the message. Some commercials about drug use have been said to reinforce stereotypical images and stigmatize drug-users, thus redu-

cing the possibility of those at risk identifying with the message.

Unintentional learning may be helpful, of course. Learning about the needs and feelings of HIV patients, for example, alerted staff to wider issues of inadequate confidentiality and lack of privacy. Devising control of infection procedures for HIV/AIDS pinpointed areas where standards of cleanliness and sterility had lapsed. At a strategic level, DHAs recognized that facilities in GUM clinics and for drug-users were inadequate for the demands being placed on them.

Situations can, however, arise in which what is unintentionally learned from a situation contradicts what it is intended should be learnt. If a nurse is taught that HIV/AIDS is not spread by casual social contact, but observes that cutlery and crockery from AIDS patients is kept separate, then the hidden message may be that AIDS is more infectious than staff have been told. If a health educator stresses the dangers of heterosexual spread, but operates from an office with posters of gay men all over the walls, then the hidden message transmitted may be that HIV is really more of a problem for gay people. A DHA may emphasize the importance of joint working with the voluntary sector, but if committees are held in the daytime, and volunteers find it difficult to attend, the implication is that they are not considered as important as the rhetoric suggests.

The importance of time

Finally in this section, we consider the role of time, and its influence on organizational learning. Individuals, particularly if motivated, learn relatively quickly; but the diffusion of that learning to groups takes longer, and to create shared understanding at organizational level will take longer still. Indeed, group or organizational learning may never happen at all if the organizational context is not receptive. The dissemination of even straightforward factual information can take a long time, but changes in attitudes, beliefs and values take far longer, and covert attachment to the old sets of values may persist. Language may reveal underlying attitudes: the same people, for example, may use different terms on different occasions to describe people who inject drugs – an indication that what has been learned is 'acceptable behaviour', rather than a new set of attitudes.

IMPLICATIONS FOR SERVICE DEVELOPMENT IN THE 1990s

We have argued that the learning that has taken place about HIV/AIDS came initially from key individuals, and was disseminated from them to their immediate reference groups, and then more widely throughout the organizations. This process has been helped by individual professional autonomy, by the provision of rewards in the form of resources, and by the creation of organizational climates in which people could learn informally as well as formally about HIV/AIDS. How-

ever, unintentional learning has also taken place, and although this has sometimes been helpful, what has been learned unintentionally may sometimes have been at variance with what was intended. In particular, entrenched attitudes and beliefs have been more resistant to change than have superficial behaviour patterns.

Finally, we have emphasized the considerable time it has taken for these processes of learning to occur. The mobilizing function of the sense of crisis has been crucial, but the time taken, even in high prevalence areas, for learning to diffuse through to organizational level poses important questions for the future. Districts with an apparently low prevalence of infection may not perceive HIV/AIDS as an urgent issue for them, and service development in these localities is likely to be driven only by the availability of resources specifically for HIV/AIDS services.

In addition, the crisis-driven learning of the eighties was in the main stimulated by clinicians of considerable prestige and influence, with access to high-level people and committees. The influential position of these clinicians meant that their individual learning was diffused more swiftly. They had expert status, and their opinions — based on clinical experience — carried weight. But these product champions may be less well-placed to drive continuing change and learning in the 1990s: they may, for example, no longer occupy such strategic positions as HIV/AIDS services expand, changing from being new to routine services. Every District will of course soon have its complement of AIDS Coordinators, Health Education Officers and others. They will all have their own reference groups and networks, but most do not have high professional status (unlike doctors) and have not

been appointed at high grades (unlike general managers). It remains to be seen whether this group will be as effective in diffusing learning.

The other crucial element has been the availability of new funding specifically for HIV/AIDS services: this has been a powerful motivator for learning amongst clinicians and managers alike. In a climate of financial stringency, it may be absolutely crucial to continue to fuel development from the centre, particularly in the field of prevention, in order to ensure that resources and management interest do not get diverted. The paradox is that just as HIV/AIDS may be dropping down managerial agendas, the organizational and management issues may be becoming more, rather than less, complex, and the need for learning increasing, rather than diminishing. The mechanisms which have encouraged learning in the 1980s may no longer be appropriate for the 1990s, but new ones must be devised.

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Entry 5.7, page 89/90

AIDS and Local Authority Social Services Departments

INTRODUCTION

During 1986–87, the development of community care for people with AIDS and HIV infection became a priority, both to reduce the demand on high-cost in-patient services, and to meet the social needs which were becoming recognized as arising from HIV infection and illness. There was considerable speculation as to the appropriate role for local authorities, but actual policies were only just beginning to emerge and their cost implications were unknown.

At the end of 1987, the Department of Health commissioned the Personal Social Services Research Unit (PSSRU), based at the University of Kent, to undertake a study to investigate the consequences for local authority Social Services Departments (SSDs), particularly in relation to the costs of direct services. A major part of the study was a survey of ten local authorities which were taking the lead in terms of formulating policy. The research uncovered a range of approaches, sometimes involving several local authority departments as well as new models of collaboration with the voluntary sector. Partly because of uncertainty, actual expenditure in 1987/88 was far lower than most departments considered appropriate.

These findings informed the Department of Health's bid to Treasury for 1988/89. As a result, a second, smaller study of five local authorities in the 'second wave' was undertaken to discover how successfully policies were being transmitted to SSDs which had had less initial commitment; and to look at the consequences of the first round of the special AIDS funding, which had been made available to local authorities to provide services for people with HIV/AIDS.

NEEDS

The needs of an adult diagnosed with HIV infection are not purely, or — initially at least — even primarily medical. As with many chronic conditions there are major social consequences and these are progressive:

- At the time of diagnosis, shock, anxiety, depression, anger and guilt will require skilled counselling. Many people experience a need for continuing support, and at least to be among others who understand the problems.

- There will be many practical adjustments regarding work, family, sex and infection control to be made. In time, these may become compounded into major housing, domestic, employment or financial difficulties, including loss of home or job. All of these are made worse by the fact that HIV infection occurs predominantly among groups of people who already experience other social problems. Unemployment, harassment, loss of housing, financial difficulties, family discord and social isolation are commonly reported problems either caused or exacerbated by HIV status. In addition, such problems will affect the partner and/or family of the affected person, who may subsequently also need help.
- Certain measures need to be taken in order to delay or prevent progression of the illness, which, in addition to medical management, may involve social care such as the provision of warm, secure accommodation; healthy diet, rest and exercise; and social support.
- When HIV-related illness advances, there is likely to be a need for surveillance and contact; support with domiciliary and personal care tasks particularly following hospitalization; help with mobility including transport; day care, respite, residential care and night-sitting, both to give relief to the affected person and to carers. These things are necessary in order to permit continued living at home and to maintain independence.

LOCAL AUTHORITY SOCIAL SERVICES

SSDs at the centre of the initial epidemic, in west London and in certain other cities, initially responded by adapting conventional services. *Social work* is one of the main services to become involved. Two models of social work organization seem to have emerged: firstly, specialist social work by a hospital-based team and secondly, community social work by generic social workers. One advantage of the first model is that people diagnosed HIV-positive can be referred directly from the hospital ward or clinic to the hospital social workers. Thereafter, they are likely to have continuing involvement with the hospital, and hospital social workers can provide a continuity of support — from counselling at the time of diagnosis through to rehabilitation.

However, hospital social workers do not normally undertake casework for people living in the community, and for this reason a number of authorities have preferred to develop community services. The usual pattern is that some workers in general social work teams specialize with AIDS-related clients, which in practice requires intervention outside the hospital setting. Case management has proved difficult, particularly because clients' needs are likely to involve a number of agencies; and community social work often resembles what has been described as a 'travel agent' rather than 'conducted tour' model of intervention — a model in which cases are constantly referred onwards. For example, HIV infection frequently results in housing difficulties, and, in practice, social workers can do no more than make a referral onwards to housing departments or associations. Lothian is the only authority to involve social workers in housing decisions, through a supported tenancy scheme.

Home care is the other major direct social service to be provided for people with AIDS. Successful models of both specialist and generic care have been developed. Some authorities, like Lambeth, have established a specialist home care team linked directly to hospital discharge in order to speed up response and manage care at a particularly crucial time. On the other hand, areas already offering an up-rated community care assistant scheme may prefer generic home care, which enables the 'burden' of this client group to be spread; such teams may maintain continuity of contact even during hospitalization. Specialist training for members of staff in teams like these is essential.

Home care allocations tend to be high — in our survey the average was eight hours per week. One reason given was the stress of working with young, terminally-ill clients, for whom emotional support is inextricably linked to long-term practical care.

Occupational therapy also plays an important part in maintaining independence, and may be involved in the provision of gadgets to assist simple tasks, and adaptations to the home. Bus passes, taxi permits and telephones also add to mobility and independence.

At the end of 1987, it was estimated that the total recurrent social services expenditure in England on services for people with AIDS and HIV infection (excluding prevention and health education) was equivalent to about £1.5m. per annum — £2,300 per annum per person with full-blown AIDS. This was generally reckoned to be far less than required and typical SSD plans at the time averaged more than twice this amount¹; by the end of 1989, the per capita direct expenditure was undoubtedly much higher still. The reasons why funding was initially low were partly financial and partly organizational:

- SSDs had just begun to accept responsibility and to organize to meet needs, and were faced with lack of reliable information about the scale of need, uncertainty about the appropriate intervention, and major training and staff problems.

- The AIDS epidemic in England appeared first in inner-city areas which were under financial pressure during the 1980s: this made innovation difficult.

But it was also because SSDs were, and still are, not entirely suitable providers of care²:

- Local authorities found that several of their conventional services were not able to provide acceptable care, nor were they sufficiently flexible to deal with the episodic nature of the condition, even though SSDs believed these forms of services were clearly needed. This included meals, day and residential care.
- People with HIV infection have been wary of social services, with fears about maintenance of confidentiality being a major problem. Only a minority of people with AIDS ever approached local authority services, perhaps as few as one in four, and then usually for help with housing. The reason for higher funding was therefore not to provide more for the people who were coming forward, but because it was believed that many more people, including those with HIV-related illness but not diagnosed AIDS, could benefit from social services.

These obstacles were not resolved as AIDS spread beyond the original centres of the epidemic and other local authorities were faced with the problem. Indeed, in some respects the difficulties increased, as the epidemic began to become apparent in new exposure groups which had their own reasons for reluctance to seek statutory help³:

- Conventional service delivery presents particular difficulties with active injecting drug-users who frequently have multiple problems of finance and accommodation. Staff have reservations about the practicality of help, and make reference to 'chaotic lifestyles'.
- HIV-positive mothers are likely to fear having children 'taken into care'.
- People from ethnic minorities are reluctant to seek help, or even to accept that they are at risk of HIV infection. There are often strong cultural taboos, particularly against homosexuality. It has been suggested that this is the reason why relatively few HIV-positive black people have been seen by SSDs in the UK, but current experience in the USA suggests that ethnic minority groups are vulnerable to the spread of the virus.

LOCAL AUTHORITY AND VOLUNTARY ORGANIZATION PARTNERSHIPS

When the Department of Health provided special funding to establish services for people with HIV/AIDS, SSDs turned to voluntary organizations for help in providing more acceptable social services. These organizations had been successful in creating help-lines, self-help groups and some befriending arrangements; and, in the case of the London Light-house, had demonstrated the ability for large-scale

fund-raising. There were a number of simultaneous initiatives in creating *service centres*, which would provide for an entire range of needs under one roof, with open-door access. During 1988 and 1989, eight such centres opened in London and the South-East, while two are at an advanced planning stage. One, the Kobler Centre, is health-authority-based, and River House in Hammersmith is a joint local authority and voluntary venture, while the remainder are all founded by voluntary organizations but run with the aid of substantial grants from local and health authorities.

Typically, the smaller centres offer a drop-in day-centre, which is the point of reference for a variety of specialist services often provided directly by local or health authorities, such as nursing or social work. The three biggest centres all provide beds for a period of residential care. The Kobler Centre is effectively a day-hospital with extended facilities. Mildmay Mission and London Lighthouse are centred around residential care, although the latter now offers a full range of services and indeed may be the largest facility of its type in the world.

As a result of supporting the development of these services in the voluntary sector, a very large proportion of SSDs' recurrent expenditure for this

client group (perhaps as much as one third) is now distributed through grant aid to the voluntary sector. So far, SSDs have been content with relatively little input into the development of these facilities; but for a number of reasons this is not an appropriate basis for the long-term, particularly given the White Paper (*Caring for People*) proposals for contract funding of voluntary organizations. Difficulties may arise in reconciling this approach with the voluntary sector's fears that such changes will destroy their ethos of accountability to users and open-door access⁴.

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The AIDS Costing Project

INTRODUCTION

In the UK, funding earmarked for health authorities to help them cope with the demands posed by HIV/AIDS was introduced by the Government in financial year 1985/86. At that time, about £1.9m. was made available; of this about £0.7m. went to the three Thames regions where the majority of HIV/AIDS patients were being treated. Five years later, the total earmarked funding for England alone had reached £130m.

An accurate estimate of the costs in the NHS due to HIV/AIDS is essential if appropriate decisions are to be made on the scale and allocation of funding at national and local levels. The *AIDS Costing Project* was therefore established with the aim of providing estimates of the cost of HIV/AIDS incurred by health authorities. In the paragraphs that follow, some of the problems of AIDS costing are discussed, together with the project's design and methodology. Several approaches to costing were investigated; and techniques for costing on a district-wide basis were developed.

DEFINING THE AREA OF STUDY

A recent trend in some District Health Authorities (DHAs) has been to integrate most acute hospital services in a district onto a single site — the district general hospital. The underlying objective has been the effective use of general functions, such as pathology, pharmacy and X-ray, and to promote connections between specialities and departments. The costing of different specialities, treatments or types of patients involves a breakdown of the total cost of this integrated service. If the service were less integrated — if, for example, there were large numbers of hospitals for specific specialities or classes of patient, like the old tuberculosis (TB) hospitals — a statistical and financial basis for costing specialities would be more readily available.

But in general, no HIV/AIDS speciality exists, with the result that the boundaries of the HIV/AIDS service are difficult to delineate. Many sectors of the NHS are involved in HIV/AIDS problems including, in particular, the services for sexually-transmitted diseases, clinical immunology, infectious diseases, chest medicine, gastro-enterology, radiology, oncology, drug dependency, haemophilia, and the

numerous branches of pathology. The conditions that may be suffered by HIV/AIDS patients are wide-ranging and the implications of the disease include aspects of treatment, health education, infection control and preventive medicine. Many services are therefore affected by HIV/AIDS, directly or indirectly: in operating theatres, for example, enhanced infection control procedures may be needed, which are time-consuming and therefore costly.

Analysis of cost variations between several districts and hospitals (in the light of their varying levels of provision) has enabled calculation of typical costs of managing patients in different NHS specialities. In the case of HIV/AIDS, however, most treatment is still carried out at a small number of inner-London teaching hospitals, and in a few non-metropolitan districts; this would not provide sufficient statistical variation to derive typical costs. *It was clear therefore, that the costing of HIV/AIDS required detailed analysis of either HIV/AIDS patient records, or of the working practices of selected hospitals and districts in relation to HIV/AIDS.*

COSTS OF MANAGING INDIVIDUAL HIV/AIDS PATIENTS

HIV/AIDS patients generally undergo a variety of investigations and treatments, and the costs involved may be atypically high, partly because of the need for stringent infection control procedures. A patient may be seen by a consultant or other health care professional, but the patient records give no measure of the time taken over these consultations. All this makes the process of costing individual HIV/AIDS patients retrospectively from patient records lengthy and sometimes imprecise.

In the past, much of the work carried out under the general heading of 'the cost of HIV/AIDS' has concentrated on calculating the cost of management of individual AIDS patients. Some early studies sampled patients who had died, and who therefore could be costed from AIDS diagnosis to death. Unfortunately, these patients were atypical in that their life expectancy was as short as six months, leading to a relatively short amount of time spent in hospital. By contrast, those AIDS patients who survived longer were usually omitted from the costed group.

One possible solution to this problem is to select a

group of patients who were diagnosed at a particular time, and to follow this group until death. The *AIDS Costing Project* studied patients with AIDS who were diagnosed at one of four London teaching hospitals in 1984 and 1985, and who had most of their treatment in the UK. From the available information, it seems that, of 107 patients in the sample, 7 or 8 were still alive at the beginning of 1990. It is sometimes difficult to ascertain the current status of patients; they may have moved house, for example, and this leads to problems in documenting treatment given to patients at the new hospital. In 1988, it was estimated that AIDS patients had a mean total AIDS-related length of in-patient stay of 91 days, and an anticipated mean survival time from diagnosis of about 450 days. At 1989/90 prices, cost-per-day of an in-patient stay was in the region of £275, giving an overall mean *in-patient* cost for these early patients, diagnosed in London in 1984/85, of about £25,000. The figures for this group are already dated, because methods of treating AIDS patients are being continually improved, the length of the typical in-patient spell is falling, survival times are apparently increasing and because we cannot be sure that patients diagnosed in the early years of the epidemic are representative of patients being diagnosed now. However, the survival and length of stay of a small sample of patients diagnosed during 1987, after the introduction of *Zidovudine* (also known as AZT) – the only drug licensed for AIDS treatment in the UK – is now being investigated, and comparisons will be made with the 1984/85 group.

DISTRICT-WIDE HIV/AIDS COSTS

It is not appropriate to equate ‘the cost of HIV/AIDS’ to a health authority solely with the cost of managing HIV/AIDS patients, because many costs are not directly related to the care of individuals. For instance, pre-test counselling and HIV testing is available to numbers of people, some of whom will turn out not to be infected by HIV. HIV-infected (HIV-positive) people may require considerable attention – primary health care, counselling, social support – before they develop HIV-related illness. Haemophilia Centres, for example, are spending far more time at present with patients who are HIV-infected, but as yet without HIV-related illness, than they are with AIDS patients. Most of the costs of infection control, health education and prevention apply to groups of the population, and so cannot be attributed to the care of individual HIV/AIDS patients even though individuals may benefit.

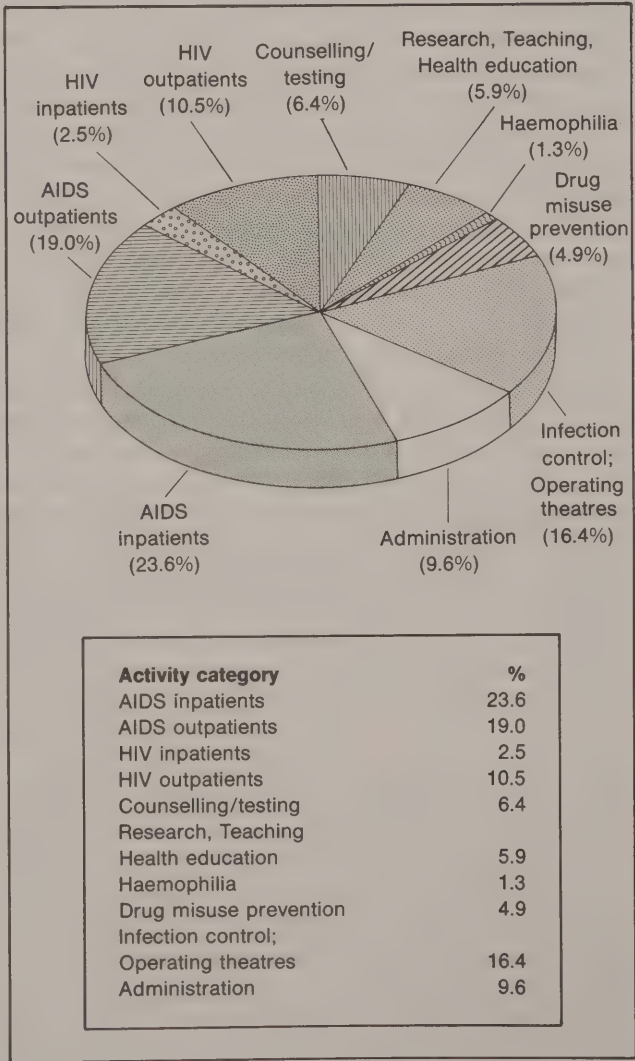
For all these reasons, the approach chosen by the AIDS Costing Project was to investigate the global financial impact of HIV/AIDS on a number of districts, by extracting HIV/AIDS costs from total district revenue costs. Given the time-consuming character of this kind of work no more than three districts could be investigated – Riverside, Oxfordshire and Brighton. These three were chosen, not because they are typical of the 192 health districts in England, but because

HIV/AIDS problems are already having very significant impact on them. Riverside is one of the three inner London districts that together still care for as many as half of all the AIDS patients in England; Oxfordshire has the largest Haemophilia Centre in the country (– haemophiliacs were an early ‘at risk’ group for HIV infection, because they were treated with blood products); while Brighton is one of the non-metropolitan districts most affected by HIV/AIDS problems.

The activities of each district were investigated to assess what HIV/AIDS-related work was being done, in which departments, the time taken and the cost of this time, and what materials – such as drugs, reagents and medical, surgical supplies and equipment – were being used for HIV/AIDS purposes. Both the hospital and community health sides were examined. An overhead element was allowed, but as these studies have centred on revenue costs, capital charges (the average annual cost of hospital accommodation and large equipment) were excluded.

It was possible, by this method, to determine cost estimates for each of the districts under study. In Brighton, for example, it was estimated that HIV/AIDS

Figure 2.1: HIV/AIDS Costs in the Brighton District by Activity Category 1989/90



related costs were slightly over £1.5m. in 1989/90. This was about 2.2 per cent of the district revenue expenditure, so even in this district outside central London, HIV/AIDS was beginning to have a significant impact. Figure 2.1 shows that expenditure on AIDS itself is only about 43 per cent of the HIV/AIDS total, or about 47 per cent — if its share of administration costs is included. It is significant that nearly 40 per cent of the global costs were not related to individual HIV/AIDS patients, but were devoted to more general services, such as infection control, health education and drug misuse prevention.

In Brighton in 1989/90, each AIDS patient cost about £18,000 per year to manage (or about £20,000, if we take into account their share of administration costs). This is comparable to that of the other districts investigated. The cost of caring for AIDS patients from diagnosis to death also, of course, depends on the mean survival time — probably now around two years. On the basis of these calculations, it is possible to say that the cost of management of a person from AIDS diagnosis to death is estimated very approximately to be in the range of £35,000–£40,000 at 1989/90

prices. This does not include costs incurred in the pre-AIDS (HIV-positive) stage, nor costs unrelated to individuals.

CONCLUSIONS

The results of the Project suggest that 'the cost of HIV/AIDS' is best established from global district cost totals, which include the costs of management of individuals and the costs of services provided for groups of people. The costs of management of individual HIV/AIDS patients underestimates the total cost of HIV/AIDS to a health authority. Using the cost extraction method, it is estimated that in England, the annual cost of an AIDS case is around £20,000 (at 1989/90 prices). The overall cost of HIV/AIDS to the hospital and community health services may be more than double the AIDS patient costs. With numbers of AIDS cases rising, these figures suggest significant public expenditure implications for the future.

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AIDS and the Future GP

The Acquired Immune Deficiency Syndrome (AIDS) poses a major challenge to health care in the UK. Since confidential reporting was started in the UK in 1982, the cumulative number of cases of AIDS has risen steadily to reach over 3,548 by July 1990. For every patient with AIDS, there may be another 50 infected with the Human Immunodeficiency Virus (HIV). Given this large reservoir of infection, the AIDS epidemic will continue to grow whatever our success in preventing further spread of the virus.

General practice has an important part to play in both health education and health care provision. In the course of their work, general practitioners (GPs) come into contact with a substantial proportion of the public. This affords an excellent opportunity to inform people of the nature of HIV infection and to advise on its avoidance. In addition, GPs are ideally situated to provide the long-term care and support needed by patients with HIV infection and their families.

Given the importance of this work, it is reasonable to ask whether general practice is able to meet the challenge posed by AIDS. Recent surveys suggest that many of the GPs currently in practice lack the necessary knowledge, skills and motivation to care for AIDS^{1,2}. What then of the next generation of doctors whose task it will be to bear the brunt of the epidemic? Are present vocational training programmes ensuring that new GPs are better prepared than their predecessors to cope with AIDS?

There has been little evaluation of the outcome of vocational training – certainly, none has been reported of the adequacy of learning or teaching about AIDS. However, some insight into the likely quality of teaching was offered by a survey we carried out among the vocational trainers in general practice of the South West Thames Region³. It is known from previous research that the example set by vocational trainers can exert a strong influence over the practice of their trainees. The knowledge, attitudes and response to AIDS of trainees might therefore reflect those of their trainers.

Our findings suggested that as far as knowledge, skills and attitudes to AIDS were concerned, trainers did not differ appreciably from their non-training colleagues³. The problems present in both groups included: uncertainty about safe taking of blood samples and sterilization procedures; lack of knowledge about some aspects of AIDS; hesitance in

eliciting patients' sexual histories; and reluctance to care for Injecting Drug-Users (IDUs). In addition, 43 per cent of trainers and 55 per cent of non-trainers said they did not feel competent to offer AIDS counselling and advice. The reasons given included insufficient knowledge about AIDS (40 per cent doctors) inadequate counselling skills (40 per cent doctors), and reluctance to offer counselling (20 per cent doctors). These findings were discouraging in that they suggested that vocational training may not provide future GPs with the role models or clinical experience they need to meet the demands posed by AIDS.

In order to assess the need for additional or alternative teaching on AIDS in vocational training, we carried out a postal questionnaire and telephone survey of the knowledge, skills and attitudes of GP trainees and their trainers in seven health regions of England and Scotland. The regions were selected to provide diversity in the prevalence of AIDS and HIV infection, and in the patient groups most commonly affected (i.e. homosexuals and drug-users). Completed questionnaires were received from a total of 614 (64 per cent) trainers and 537 (60 per cent) of their trainees. Interviews were conducted with 93 pairs of trainers and their trainees.

The findings show that GP trainees resemble trainers in their lack of knowledge about HIV/AIDS, inappropriate attitudes towards HIV/AIDS prevention, and lack of skills in HIV/AIDS care. For example, a fifth of trainees and a third of trainers failed to answer correctly more than 5 of 10 true/false questions regarding AIDS. Half the trainees and a third of the trainers were unwilling to accept IDUs onto their lists. A quarter of trainees and a fifth of trainers said it was never easy for them to discuss sex with a homosexual patient. A third of trainers and three-fifths of trainees felt unable to counsel patients found to be HIV-positive.

Although trainers and trainees were broadly similar in their strengths and weaknesses in dealing with AIDS, there were no significant associations between the knowledge, attitudes, and skills of individual trainers and those of their trainees. Thus there was no evidence that the trainees' approach to AIDS was directly modelled on that of their trainers. How then did trainees acquire knowledge about AIDS? We found that certain educational activities were associated with more favourable outcomes: trainees who

had participated in workshops on HIV/AIDS were more willing to provide care to IDUs, and more confident in their ability to counsel patients found to be HIV-positive.

These findings conform to accepted relationships between the type of teaching method and the category of objectives likely to be achieved. Formal lectures and tutorials are useful in teaching knowledge and demonstrating skills, whereas small group work is effective in challenging attitudes and promoting self-awareness. We have shown elsewhere that a suitably designed workshop can be effective in improving the attitudes of primary health care workers towards HIV/AIDS prevention and care⁴. Course organizers and GP trainers could make use of our findings in planning future vocational training by applying the following simple educational principles:

- Relevance, and identified 'need to know', speeds learning. Creation of a need to know in adult learners with experience often requires them to be confronted with their present behaviour and its origins. A small group with an experienced leader is a suitable arena in which to achieve this.
- Full, rather than partial, mastery of each step makes total learning more meaningful. As a consequence, it is important that learners who have identified a need to know are provided with a comprehensive but controlled flow of information concerning the subject. In most localities there are workers specially trained in providing such information.
- People learn more when each step is clearly identified and immediately strengthened and reinforced by practice. This can initially be provided within the small group sequences of a workshop and further reinforced by practice in real life. In particular, skills and attitudes are more readily applicable to other diseases than in knowledge, so that ability in counselling and willingness to discuss sexual matters can be developed in consultations with a range of patients.

- It is an important responsibility of teachers to point out to learners fresh opportunities to rehearse new skills. In vocational training for general practice this requires cooperation between one-to-one trainers and the organizers of release courses.

Our research shows clearly that there is a need for additional teaching and learning about HIV/AIDS in the vocational training of GPs. The present lack of commitment and expertise in managing HIV/AIDS is worrying, not least because it is a good exemplar of the kinds of attitudes and skills which form the core of general practice. Doctors' lack of confidence in their ability to counsel HIV-positive patients is particularly regrettable, given the fact that counselling is a skill fundamental to much of the work of general practice. Similarly, a reluctance to elicit sexual histories must raise doubts about preparation for a much wider range of discussions with patients. A carefully planned, educational programme would do much to improve the care of HIV/AIDS patients by GPs, and the rewards for doing so may extend far beyond this condition to encompass the whole of general practice.

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HIV and General Practitioners: a National Sample Survey

INTRODUCTION

This paper describes the first national survey of general practitioners (GPs) on the subject of HIV infection and AIDS. At the time the survey was commissioned, in 1987, there was considerable coverage of AIDS in the medical and lay press, and great uncertainty about the future course of the epidemic. Few GPs, except in London, had cared for patients with AIDS or who were HIV-positive; but, as the total number of sufferers grew, it was expected that more and more GPs would find patients presenting to them with worries about possible HIV infection, as well as some who were already infected, and some who would have progressed to AIDS itself.

Almost nothing was known about how ready GPs were to meet this demand, although there had been a few regional and local surveys of GPs' attitudes and intentions, mainly in the London area. The Department of Health therefore commissioned the Health Care Research Unit at the University of Newcastle upon Tyne to conduct a national survey of the current experience and future intentions of GPs, with a sufficient sample size to make inter-regional comparisons possible.

AIMS AND METHOD

The Survey had two aims:

- To determine the extent and nature of GP contact with people with HIV infection, AIDS, or with worries about HIV infection or AIDS.
- To determine practitioners' knowledge, beliefs and intentions towards a number of HIV and general practice-related issues.

A 20 per cent sample of all GPs in England and Wales was selected. This was balanced by Family Practitioner Committee (FPC) area, and by the number of principals in the practice: in a practice of five partners, for example, only one would be included in the Survey. The Survey was conducted entirely by post, using a list of names and addresses provided by the then DHSS Statistics Unit. Every sampled practitioner was sent a questionnaire divided into eight sections:

1. Age, qualifications and practice details
2. Extent of contact with HIV patient groups
3. Effects of HIV on the practice
4. Knowledge of HIV, AIDS and related issues

5. Provision of health education and counselling
6. Views of HIV testing and confidentiality
7. Management of HIV-positive patients
8. Personal reservations and practice policies

In devising the questionnaire we were able to draw on some work already done in the South West Thames Region, but many questions had to be derived from first principles, requiring stages of piloting: in the early stages, face-to-face interviews were carried out with selected practitioners. The questionnaire was posted with a reply-paid envelope, and up to two reminders were sent to non-responders. A second form, called a consultation diary, was sent to a sample of those who replied to the questionnaire, and who had indicated some degree of contact with patients having or concerned about HIV. Recipients of the diary were asked to provide, for a week, brief details about each consultation in which they considered HIV or AIDS to play a part. (A parallel survey, using the same questionnaire, was carried out in Scotland by the Health Services Research Unit at the University of Aberdeen, funded by the Scottish Home and Health Department: the results reported here are only for England and Wales).

RESULTS

Response rate

The questionnaire was completed by 3,427 out of 5,359 recipients, a response rate of 64 per cent, after discounting questionnaires which were undelivered. This is comparable with other large surveys of GPs, but not so high as to exclude the possibility that those who responded were not typical of the whole, although there was no definite evidence that this was the case. The consultation diary also achieved a response rate of 64 per cent of those to whom it was sent.

Consultations related to HIV infection

Table 2.5 details the number of respondents who knew of HIV-positive patients or patients with AIDS within the practice. GPs in the four Thames regions more frequently knew of patients in these categories than colleagues working elsewhere.

During the month preceding receipt of the questionnaire, 4.5 per cent of respondents had been consulted by HIV-positive patients without symp-

TABLE 2.5: Respondents who knew of one or more HIV-positive patient within the practice

	Percentage who had patients with:		
	Asymptomatic HIV infection	Symptomatic HIV infection	AIDS
Four Thames regions	31.7*	10.0*	12.2*
Other regions	19.2	3.9	4.3
TOTAL	22.7	5.6	6.5

* $p < 0.0001$ versus other regions

toms, 1.7 per cent by symptomatic HIV-positive patients, and 1.6 per cent by patients with AIDS. Substantially more respondents had seen patients with worries about HIV infection or AIDS; 44.3 per cent of respondents reported that they had had such consultations in the last month. This varied from 37.4 per cent of respondents in the Trent region to 56.9 per cent in South East Thames. Practitioners working in the four Thames regions were more frequently consulted by patients with worries than practitioners working elsewhere (50.2 per cent compared with 42.1 per cent, $p < 0.001$).

Extrapolation from the reported consultations suggests a consultation rate for HIV (including those with worries about HIV) of 6.5 per 1,000 patients per year, or more than 300,000 consultations over England and Wales — an average of one per month per practitioner, though with considerable regional variations.

Diary of HIV-related consultations

The diary, completed by 458 practitioners, recorded a total of 273 consultations with 267 different patients during the study week. HIV-related consultations accounted for approximately 1 in 220 surgery consultations and 1 in 580 home visits. Table 2.6 shows who the patients were; no one group dominates. Almost half the consulters were not thought by practitioners to fall into any of the recognized risk categories.

TABLE 2.6: HIV-related consultations over one week by patient characteristics

Patient group	Percentage of consultations (n = 273)
1. Homosexual men	19.0
2. Injecting drug-users	16.5
3. Sexual partners of groups 1, 2, 4, 5, 6 or 7	10.3
4. Sexual partners of heterosexuals with known exposure abroad	4.4
5. Recipients of infected blood	3.3
6. Bisexual men	2.6
7. Prostitutes	1.1
8. None of the above	42.9

Advice or information was the commonest reason for the consultations recorded by 38.1 per cent of patients; 16.5 per cent requested the HIV-antibody test, 9.9 per cent presented with drug-related problems, and 8.1 per cent presented with symptoms which they thought were of AIDS.

Effects on practice

About 60 per cent of respondents said they had started wearing gloves for taking blood in response to HIV; 10 per cent had always done so and the remainder were undecided or not intending to do so. Gloves were almost universal for internal examinations, even before HIV, and very few practitioners intended wearing gloves for non-invasive examinations. Some 15 per cent had stopped resheathing needles as a result of HIV; 45 per cent had made this change before HIV.

Knowledge

A range of 15 true/false questions were asked; the respondent was offered an 'uncertain' reply option as well. The questions ranged from ones about the infectivity and virology of HIV, which were answered correctly by most respondents, to questions about clinical aspects of AIDS, about which respondents registered a higher percentage of uncertain and wrong answers. The typical respondent scored nine correct answers, three incorrect and three uncertain; younger practitioners did slightly better than older ones. A commentary on the questions was sent after the event to the 85 per cent of respondents who requested it. Table 2.7 illustrates a few of the questions and the responses obtained.

TABLE 2.7: Knowledge of HIV infection and AIDS: sample questions

Statements	Correct answer	Percentage answering correctly
All blood intended for transfusion in the UK is tested for HIV antibodies	True	95
After HIV infection it can take three months until antibodies can be detected in the blood	True	91
In injecting drug-users the most common presenting symptom of AIDS is Kaposi's sarcoma*	False	23

*a malignant condition often presenting on the skin

Health education and counselling

Most practitioners said they did, or would, provide opportunistic health education for patients in recognized risk groups. In this context, discussion of the patient's sexual practices or intravenous drug use, as appropriate, would obviously form an important part. Twelve per cent of practitioners stated they never found it easy to discuss sexual practices with a heterosexual patient (male or female); this rises to 33 per cent when discussing with a homosexual man or woman. Female practitioners found discussing homosexual practices less easy than did male practitioners. Discussing drug use was never easy for 12 per cent of respondents. Most GPs claimed to provide counselling for patients at risk and their families, although it is not possible to judge from a postal survey whether there is a common understanding of the term 'counselling'.

Blood testing and confidentiality

About 90 per cent of practitioners favoured HIV-testing being offered routinely to those in risk groups, including prostitutes and partners of those known to be HIV-positive; 62 per cent thought pregnant women should be offered testing; and 22 per cent thought everyone should. As for testing without consent, about one-third of respondents were in favour for the main risk groups, and 30 per cent were in favour for pregnant women. The policy of anonymous testing of samples taken for other purposes (not introduced at the time of the survey) was favoured by 56 per cent, with 25 per cent against. Most practitioners wanted to be informed of a patient who was diagnosed HIV-positive elsewhere; 40 per cent would want this information even against the patient's wishes. A slightly smaller proportion were in favour of informing medical colleagues, against the patient's wishes, of a diagnosis made in general practice. In contrast, very few were in favour of informing the patient's sexual partner, family or employers without consent, and hardly any respondents were willing to reply to insurance company enquiries about a patient's 'at-risk' behaviour or antibody status.

Care and management of patients

Three-quarters of GPs would be willing to be involved in some way in the care of a patient who developed AIDS, and only six per cent definitely would not. We asked questions about whether practitioners would knowingly accept certain categories of patients onto

their lists, or remove such patients if their status became known. Table 2.8 summarizes the results. *Less than half* of respondents would be willing to take on an injecting drug-user.

SUMMARY

The results of this one-off survey in 1988 reveal a profession which is willing to rise to the challenge of HIV infection and AIDS, and which is already encountering patients with worries or HIV infection. However, knowledge was limited, especially of the clinical aspects of AIDS — predictably, since few at that time had seen a case. A programme of postgraduate training in handling consultations which touch on the patient's sexuality is needed, particularly in regard to homosexual patients. Similarly, the management of injecting drug-users, which many GPs are reluctant to handle at the moment, needs to be the subject of training. Policy about who should be informed of a positive test result needs clarifying in the minds of GPs.

Subject to these specific reservations, general practice should be able to cope with the growing number of actual and potential HIV-positive patients, and share in the care of patients with AIDS. They are in the best position of any health workers to provide health education on HIV/AIDS to the healthy population, and so to counter the ignorance which is still widespread.

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TABLE 2.8: Acceptance onto GP lists and removal from lists

Risk group	Percentage	
	Would knowingly accept	Would remove if discovered
Homo/bisexual man	93	1
Haemophiliac	98	0
Prostitute	89	1
HIV-positive patient	83	1
Patient with AIDS	78	1
Injecting drug-user	48	6

Copies of the full report, *A national study of HIV infection, AIDS and general practice*, report number 36, are available from the Health Care Research Unit (see entry 5.14, page 94/95), price £5.00, including postage, in the UK.

Extracts of this article appear with permission of the editor, *British Journal of General Practice*.

Chapter 3

Child Care Theme Research

In some respects, work on the child care theme presents a contrast to the AIDS programme. Research in support of its child care policies has featured in the Health Department's research programme since its inception. Child care research has therefore had time to develop and mature; and skills, disciplines and sciences have combined to produce authoritative research, and effective dissemination. The ten articles included here give some impression of this, while the theme coordinator's overview presents an account of current and future strategy in this area.

Two strands of research which currently predominate in the child care programme focus on the prevention of child abuse and the treatment offered to its victims, and the implications of the Children Act 1989 across the child care field. Monck's article reports the interim results of an attempt to monitor the outcome of a particular model of treatment offered to *sexually abused children* and their families, and highlights the problems which have to be overcome if collaboration between researchers and clinicians is to succeed. Smith's study, in contrast, presents an account of the behaviour and attitudes to sexuality of normal families, as a backdrop against which abnormal behaviour is to be examined and better understood.

Four articles are concerned with aspects of policy and practice which have been highlighted by the Children Act 1989. Murch reviews some of the 'spin-off' findings of a study of the processes by which children are represented in court, and traces their impact on the development of provisions in the Act. The general duty placed on local authorities by the Act to safeguard and promote the welfare of children in their area who are in need is the focus of Gibbons' article. This gives a brief account of the Family Support

research at the National Institute for Social Work, designed to describe contrasting ways in which social services departments respond to families in need by providing preventive services. Garnett's study looks at the situation of young people leaving care — again, in the context of the Act. Finally, Bullard and Malos report on a study of the use of custodianship (abolished by the Act) and suggest that the group of families and types of placements uncovered by the research deserve greater attention by policy.

The Thomas Coram Research Unit has been funded by the Department since the early 1980s to undertake research which would contribute to the development of ideas concerning the provision of *day care for children*: Melhuish and Moss report on the progress of the study. Another major research project, dating from 1984, is the subject of the article by Bottoms and McWilliams. This focuses on their evaluative research on 'intermediate treatment' as a means of reducing criminality among children and young persons.

The last article in this group, produced by the Dartington Social Research Unit, deals with the very important issue of the *dissemination* of research findings — in this case, social work research. Issues which will be of concern to researchers and policy-makers in a number of areas — the links between research, policy and practice, problems of inter-agency and interdisciplinary collaboration — are discussed in the context of the dissemination of child care research, and form an appropriate conclusion to an account of this theme.

The views expressed in the following articles are those of the authors, and not necessarily those of the Department.

An Overview of Research on Children

There is a stimulating and varied programme of child care research which, in recent years, has produced important findings that have been influential in shaping policy, including the drafting of the Children Act 1989. The success of the programme is founded on the close working relationships between policy-makers and researchers administered through an active research advisory group, the Child Care Research Liaison Group, and regular project progress meetings. This chapter covers current and planned studies, and defines research programmes that have, or will, produce findings which are particularly influential in shaping policy. It begins with a synopsis of planned and recently commissioned work. More detailed information is provided in the illustrative articles contributed by researchers currently funded by the Department.

DH RESPONSIBILITIES FOR CHILD CARE

The Department's present responsibilities for child care date from 1971, with the setting up of Social Services Departments (SSDs) which brought together services to children with those for families and adults. The responsibility for the care, upbringing and protection of children is wide-ranging, extending to all children 'in need' up to the age of eighteen years. In the youngest age group — children up to five years of age — responsibilities are not only for children 'in need', but include pre-school services for all children.

Research is planned within a framework provided by the child care research theme, which is structured to reflect the full range of the Department's responsibilities for child care. This is set out below in terms of subject areas. They are as follows:

- Child Abuse
- Children Act 1989
- Adoption
- Under-Fives
- Children in Care
- Juvenile Delinquency, including:
 - Secure Accommodation, and
 - Youth Treatment Centres.

The child care research theme is characterized by a strong customer involvement in both the planning and utilization of research. This involvement extends back over a number of years during which there has been an accumulation of policy-relevant research.

Indeed, one of the objectives of research planning is to see research as a cumulative process, so that as far as possible, future plans are set against a framework of existing research. Where feasible, clusters of related research projects are exploited in joint dissemination exercises. The use of research by both policy makers and practitioners is related in this chapter with the description of a recent, novel approach to dissemination (see Dartington's article on page 61).

The future research strategy has been planned against a background of current work. A broad outline of the current programme of work within each subject area is presented below, followed by an account of the future strategy in that area.

CHILD ABUSE

Current programme

A major research initiative on child abuse was launched in 1987 in the light of concerns arising from the Cleveland Inquiry. Beginning with an internal discussion paper defining areas of research need, a programme was set up to highlight a variety of aspects of child abuse. It includes studies investigating the perspectives of parents and practitioners, focusing on cases both prior to and during intervention, and monitors behaviour and outcomes for both normal and 'deviant' groups. Studies were set up to address three main topic areas: service response to child abuse; the phenomenon of child abuse; and practice issues.

Service response to child abuse

The group of studies concerned with service response to child abuse is about important points of intervention and their impact on children and other family members. The projects were planned as a package of complementary, inter-related studies.

The starting point for intervention is when a case first comes to the attention of professionals and is the subject of an investigation. The Cleveland Inquiry suggested that inappropriate handling at this sensitive stage may in itself cause subsequent problems. The research study *Parental Perspectives on Child Abuse* (entry 5.6, page 88) begins at this stage and traces a sample of cases over an 18 month period. A second study (project 5.88, page 114), focusing on parental participation in decision-making, picks up cases at a slightly later stage, when a multidisciplinary case

conference is called. A third study, looking at the impact of early intervention on the child, examines the case when it has gone beyond suspicion and becomes established. All three studies measure short-term outcomes.

A further group of studies is designed to look at later stages of intervention and at medium-term outcomes. One, a study of social work decision-making (project 5.81, page 112), focuses particularly on the decision as to whether or not to remove the child from home. A second study (5.92, page 115; and article on page 40) looks at the efficacy, for victims and their families, of a specialized treatment programme at Great Ormond Street Hospital. A third study, which follows a feasibility stage, looks at longer term consequences, through a follow-up study of children who were placed on NSPCC registers in 1981 (entry 5.3, page 86).

The phenomenon of child abuse

It was recognized that a greater understanding of the phenomenon of child abuse would assist in diagnosis and in planning of services. One study, due for completion in 1990, has looked at normal sexual knowledge in children (project 5.93, page 115; article — page 43) and will help practitioners to distinguish more confidently between the normal and the abnormal of suspected child abuse cases. A second, recently commissioned, study will look at *Control within the Family*, to investigate the range of normal punishment behaviour. Further research priorities in this area are identified in the future strategy described below.

Practice issues in child protection

This group of studies focuses on the mechanisms and tools available to practitioners in child protection work. A study of *Coordination in Child Abuse* examines interdisciplinary working, which was highlighted as a matter of concern by the Cleveland Inquiry (project 5.95, page 115). A second, more recent piece of research, examines the operation of Child Protection Registers (CPRs). These serve an important regulatory purpose in child protection work, but their pattern of use varies considerably between authorities and the research aims to explain and clarify this. A further study, currently at a feasibility stage, aims to develop computer-aided methods of diagnosis in child sexual abuse.

Future strategy

Following completion of the current projects, a joint dissemination programme is planned, based on the success of an earlier dissemination programme in social work (see article on page 61). Preparatory work is already being undertaken through a regular series of seminars involving all of the DH-funded teams which serve to inform policy-makers and practice advisers of the programme's progress and of very early descriptive results.

Priorities in other child care areas make it likely that in the short-term there will be less new work in child abuse. However, some important current priority topics remain to be addressed; commissioning of these will be dependent on the availability of funds. They include:

- *The Phenomenon of Abuse*: To gain a better understanding of the factors which cause perpetrators to abuse their victims; to obtain a better understanding of the longer term consequences of abuse, and, in particular, why some victims do well and others do not; to gain an understanding of the factors associated with abuse, with a view to improving prevention; and to examine the relationship between emotional abuse and neglect, and physical abuse and sexual abuse.
- *Service Response*: Research to widen the focus from diagnosis of abuse and its immediate aftermath, to defining longer term needs and planning of services; to gain an understanding of the longer term consequences of initial intervention, including the impact of removal from home and subsequent return; evaluations of treatment and routine services.
- *Practice Issues*: Stress among social workers; the support and training of social workers in dealing with the families and victims of abuse; communication skills of staff handling child abuse cases.

THE CHILDREN ACT 1989

The Department's somewhat diverse range of responsibilities for children have recently been collected under one umbrella in the Children Act 1989. The Act brings together and codifies the legislation in respect to children, and, in some fields, extends and modifies the law. The Children Act affects most of the Department's responsibilities towards children and because research on the Act forms the major priority in 1990, it will arise in describing current research and future strategy on a range of topics.

Several studies have been relevant to the preparation of the Children Act. One study on the *Representation of Children in Court* has fed directly into the drafting of the Act (project 5.85, page 113; article on page 46). The aim of new work is to establish baseline data and to monitor and evaluate the impact of the Act to see whether it will lead to improvements for children. Research is planned in the following important areas:

Family support — prevention of family breakdown

A key principle of the Act lies in the belief that children are best looked after within the family, in their own homes with both parents playing an active part, without resort to legal proceedings, so long as this is consistent with the welfare of the child. The Act imposes a new duty on local authorities to promote the upbringing of 'children in need' within their families, by the provision of a range of forms of support. It also changes the distinction between voluntary and compulsory care.

Practitioners currently use a range of existing forms of family support, including voluntary visiting services, respite care and family centres. It is hoped that, under the Act, these will be extended and developed and that others will be added. Some current studies can be used to provide baseline data. For example, the 'Two-Area Study' (entry 5.3, page 86; also see article on page 48) provides a comparative account of family support in two local authorities with contrasting policies towards voluntary work. A study of family centres (5.94, page 115), jointly funded with the Children's Society, describes current patterns of provision at family centres and provides a profile of users.

The future research strategy will be to monitor the effect on families of new provisions for family support. Possible topics include looking at the effect of the new distinctions between voluntary and compulsory care; and monitoring the registration and inspection provisions, in both children's and private homes, as well as the new obligations to children in long-stay health or education accommodation. Projects already in the planning phase include a study of respite care, and a further evaluative stage of the family centres research.

Family support — pre-school and out-of-school services

A second service given prominence because of its importance for family support is day care and supervised activities for pre-school children and school-aged children outside school hours. The Act lays a responsibility on local authorities to provide for children 'in need' and a power to provide more support by way of advice and information. It also strengthens the duty to register and introduces a new duty to review pre-school and out-of-schools services. Future strategy includes plans to monitor registration and review provisions of local authorities in respect of day care, and to describe and evaluate after-school and holiday play schemes.

Child protection

The Act introduces a range of provisions with respect to child protection. It replaces 28-day Place of Safety Orders with 7-day Emergency Protection Orders, and tightens up the requirements for emergency protection, the duration of orders, and the ways in which these are obtained. In addition, the Act introduces a Child Assessment Order, when there is concern about a child, but immediate removal is not thought to be warranted.

The research strategy will be to monitor the new provisions for emergency protection and, in particular, to investigate how authorities handle the short period of time for action. It will also examine how the new provisions affect interdisciplinary working, whether children go home, and how many transfer to accommodation or care.

Court-related research

An important objective of the Act is to improve the handling of children by the Courts. A number of measures are introduced to this end: for example, new arrangements to reduce delays in courts and changes to the grounds on which children are considered in need of suitable 'care'. The provisions for the separate representation of the child in court proceedings are widened and strengthened.

One major study has already been commissioned to establish baseline data to enable pre- and post-Act regimes to be compared. This will monitor cases going through courts and record relevant details. A post-Act stage will compare similar cases to evaluate the impact of the Act and to see whether the changes have benefited the child.

A variety of other studies is planned, with the overall aim of determining whether the changes introduced by the Act achieve the intended improvement in the circumstances of children. Depending on the quality of applications and the availability of resources, they will include: the child's perspective in court proceedings; monitoring concurrent jurisdiction for children's cases in the courts; monitoring planning for children looked after by the local authorities under the Act, including reviews and complaints; monitoring the effects of the new supervision order residence requirement in criminal proceedings; and a closer look at the interdisciplinary practice in emergency provision, assessment and in-care proceedings.

Leaving care

The Children Act strengthens the responsibilities of local authorities to support children when they leave care. An initial small-scale study (a follow-up of an earlier study) has looked at the arrangements in three local authorities by tracing care leavers in the years 1986 and 1987 (follow-up to project 5.78, page 112; article — page 50). A further study has been commissioned to examine good practice and to compare a group of leavers going through support schemes with a similar group of young people who are not. The aim is to provide guidance to local authorities as to the best arrangements for the support of care leavers.

ADOPTION

Adoption represents the one major area of Departmental responsibility not covered by the Children Act. However, a review of Adoption Law is now underway and this is likely to lead to a change in the legislation. A research literature review undertaken by June Thornburn has been fed into the Law Review.

Current programme

Some major changes in adoption law were introduced under the 1975 Adoption Act. This brought with it a legislative requirement to monitor and report back to Parliament on the impact of major changes introduced. A set of studies was accordingly commissioned to monitor and evaluate the impact of the Act. The

studies have looked respectively at the following provisions: Adoption Allowances, Custodianship (5.82, page 113; article on page 53), Freeing for Adoption. The study on 'freeing' was widened, after its first phase, and renamed *A Study of Pathways to Adoption* (5.84, page 113). This looks at the strengths and weaknesses of the current 'process' of adoption and the findings will assist the Adoption Law Review.

In recent years, the subject of transracial adoption and placement has become a matter of concern and debate. A study commissioned in 1988 (entry 5.9, page 91) looks indirectly at this issue, studying social identity in adolescence amongst three groups of young people, respectively: white English; black Afro-Caribbean; and mixed-race group.

Future strategy

The future research strategy will investigate further the factors which contribute to successful adoption, particularly bearing in mind that many children now being adopted are likely to be older or mixed-race or of a number of ethnic minority origins. Priorities include research to look at the characteristics of successful adopters; family finding strategies; examination of how many transracial adoptions take place; whether black and mixed-race children stay longer in care; and the consequences of black or mixed-race children being brought up in different families.

SERVICES TO UNDER-FIVES AND OUT-OF-SCHOOLS SERVICE

Demographic changes mean that this area has gained importance in recent years because a higher proportion of women are returning to work early. Several studies have contributed to understanding about the effects of non-parental day care on young children. One important study examined the influence of day care on children's emotional and cognitive development (entry 5.9, page 91; article – page 55). This finds no conclusive evidence of a 'day care effect' on young children, but suggests that for very young children individual care may be better than poorly resourced group care. It also demonstrates the importance of continuity and stable carer relations to the child's well-being.

Further current studies include a study of play-groups (5.9, page 91) and a study of the support and training for childminders (5.80, page 112). A major national survey of patterns of use of pre-school provision and out-of-schools services is planned by the Office of Population Censuses and Surveys (OPCS) for the Autumn of 1990. This will provide much-needed data on the use of day care services and consumer satisfaction with them.

The future strategy is to continue to support research which improves understanding of non-parental day care for under-fives and how this affects the relationship with parents. In addition, research is planned to investigate factors which contribute to good quality care for under-fives, particularly for very

young children and to examine how social and economic changes affecting the family are likely to influence the requirement for child care services.

CHILDREN IN CARE

Current programme

The current programme focuses on the 'in care' and 'post-care' experience, which complements and extends an earlier programme of research which focused on social work decision-making on entry to care. This was the subject of a major dissemination exercise described elsewhere. A second exercise, again led by Jane Rowe (project 5.78, page 112) is now underway to bring together a group of studies which concern the placement of children in care.

Current or recently completed studies include a study of children *Home on Trial*; a recently commissioned study of *Assessment*, which looks at key points when the assessment system is triggered, and considers what types of cases are allocated to different forms of assessment and why; and a study of *Return Home* as experienced by children in care (entry 5.6, page 88). The Dartington study will trace, over a period of 18 months, the experience of a group of children returning home after periods in care.

Future strategy

The immediate priority for the future is to conduct a comparative study of residential care and family placement with the aim of discovering which forms or packages of care are most successful for which types of children. Research needs have also been identified which are concerned with reconstituted families; local authority fostering and adoption units; individual aspects of family placement; mixed-race children in care; and the translation of policies into practice in SSDs.

JUVENILE OFFENDERS, SECURE ACCOMMODATION AND YOUTH TREATMENT CENTRES

Current programme

Research has centred around two major studies. A descriptive and evaluative study of intermediate treatment due to be reported later this year (project 5.87, page 114; article on page 58) and a follow-up study of young people leaving Youth Treatment Centres. The first stage, which describes the characteristics of young people as they enter centres, has already been written up. The second stage will follow their progress through the centres. The policy objective in this area is the prevention of juvenile delinquency and the provision of cost-effective services to control offenders and reduce the risk of offending.

Future strategy

A high priority is to conduct research into the factors which protect young people who are at risk of offending from doing so. Other medium term objectives include evaluation of interventions designed to

affect family handling of a child's delinquent behaviour; monitoring initiatives to divert young offenders; and studies of patterns in female delinquent behaviour. All the studies would be expected to take account of ethnic differences.

CONCLUSION

This section broadly summarized the content of the current programme and outlined the future research strategy in child care. The research strategy will set the agenda for research planning in the next few years and will provide overall coherence and continuity. Of

course, it will be necessary to retain flexibility, to be open to possible changes in emphasis as new priorities emerge in the policy context. Plans will inevitably be subject to the availability of funds and of sound scientific proposals. However, the intention is to shape a programme which will yield a continuing stream of relevant material to inform policy-makers, the Social Services Inspectorate, and to assist in the development of good services to children.

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Elizabeth Monck
Project 5.92, page 115

Monitoring the Outcome of Treatment for Sexually Abused Children and Adolescents

The numbers of known cases of children and adolescents who have experienced sexual abuse have risen sharply in the last decade, and several professions have become involved in developing specialized treatment for the children and their families. Many cases are referred for psychiatric help, and models of family, individual and group work have been developed to meet the specific needs of the sexually abused child¹. However, relatively little is known of the outcome of such treatment, either in terms of remission of clinical psychopathology, or in terms of social adjustment. In the field of child sexual abuse, there are no published prospective studies of treatment outcome in the UK.

THE STUDY

In 1986, the Department of Health commissioned research from the Institute of Child Health into the effectiveness of the treatment offered by the Department of Psychological Medicine in the Hospital for Sick Children, Great Ormond Street, to children who had been sexually abused, and to their families.

The Department of Psychological Medicine had, under Dr Arnon Bentovim, pioneered the treatment of sexually abused children, using group work with children and their parents or carers, among other techniques. The research was planned to assess how effective this group treatment was in meeting the needs of the abused children and their families.

Since the Hospital for Sick Children occupies a regional and, in some respects at least, a national role, it was planned that the research would also provide a descriptive profile of the sexually abused children referred to the Department. There are, at present, no systematically acquired UK data on sexually abused children and their families, referred to psychiatric treatment.

All the children aged between four and sixteen years who were referred to the Department of Psychological Medicine were eligible for inclusion in the research programme, if a diagnosis of sexual abuse was confirmed by the clinical team. Sexual abuse was defined as a sexual contact instigated by, and for the sexual gratification of an adult or older teenager with a child or teenager who was either unwilling, or too young to understand fully what was happening. Cases were eligible for inclusion when the abuse had

occurred within the previous 24 months and its disclosure or discovery had occurred within the preceding 12 months; and when the offender* was a member of the household or the close family.

All the children and families who fulfilled these criteria were invited by letter to join the research, and initial interviews were planned to take place when the family attended their first clinical appointment.

In order to assess the outcome associated with group treatment, those families who were accepted for treatment were randomly allocated to two kinds of treatment: they either received family treatment alone or family treatment with additional group work. Family treatment consisted of meetings at roughly 4–6 week intervals, with those members of the family the therapist wished to work with at that time. Group treatment consisted of between 6 and 20 weekly sessions provided separately for children of different ages and sexes, and for parents. The length of the group treatment varied according to the age of the children: the youngest received 6 or 8 weekly sessions and the oldest between 18 and 20. The parents' group might include abusive parents when the clinical team were hoping to reconstitute the family at a later date.

Research interviews were held separately with the caring parent[†], abused children over the age of six years, and those offenders who attended the hospital. The research interviews covered family relationships, including the amount of warmth, confiding, quarrelling and criticism there was between the abused child and the caring parent and the abused child and the offender: demographic information about the child's family; the health and behaviour of the child, their friendship patterns, and school adjustment; information on the nature and duration of the abuse; and the quality of the parents' marriage/partnership. Parents were asked to recall whether they had experienced abuse in their own childhood or adolescence. Parents, offenders and abused children were asked to complete questionnaires on their psychiatric state, their self-esteem, and (where relevant) the quality of the adults' partnership. Schools

*The word 'offender' is being used in its descriptive, not its legal sense.

†The 'caring parent' was the adult in charge of the child at the time of disclosure. When children were rejected by or removed from their parents, and had been moved to children's homes immediately after disclosure, their key worker was interviewed in place of a caring parent.

were approached — although not all felt able to help — to provide information on the children’s progress and behaviour. The family’s social worker completed a behaviour checklist².

For those children and families who entered treatment at Great Ormond Street, a further interview was held at the end of treatment, approximately 10 to 12 months after the first interview. For these families, assessments were made by the clinical team of aspects of the family functioning and individual psychopathology of the child and other family members at the beginning and end of treatment.

The research follow-up interview contained many of the same measures as the initial interview; in addition, children and family members who had attended the Hospital for Sick Children were asked in detail about the Hospital treatment, and about treatment they had received elsewhere. Schools and social workers were asked to complete the same questionnaires on the child’s behaviour as they had supplied at the start of the treatment. Those children and families who did not enter treatment received only the initial research interview.

Over the research study period, 300 families, comprising at least 385 children and adolescents, were referred to the department after (suspected) child sexual abuse. A large proportion of the families did not meet the research criteria, or were excluded for other reasons: for example, 28 per cent never attended the hospital and the work of the clinical team consisted in providing advice to other professionals. In a small number of cases, the research team were refused contact with families by the High Court.

Out of 92 eligible families (118 children), 75 (93 children) were seen by the research team — an 82 per cent success rate. The children’s ages at referral are shown in Table 3.1.

TABLE 3.1: Age of children in the research sample on their referral to the Hospital for Sick Children with a diagnosis of sexual abuse

Sex	Age in years						Total	%
	4-7	%	8-12	%	12 +	%		
Girls	23	(30.0)	26	(34.0)	27	(36.0)	76	(100)
Boys	10	(59.0)	6	(35.0)	1	(6.0)	17	(100)
TOTALS	33	(35.0)	32	(34.0)	28	(30.0)	93	(100)

Offenders: 126 offenders were involved with the 93 children, of whom 18 were adolescents. Not all these offenders were involved in the current offence; Table 3.2 shows the relationship of the offenders to the abused children.

The nature of the abuse varied from fondling and touching to sexual intercourse and buggery; Table 3.3 shows the most frequent and the most ‘severe’ forms of abuse for the 93 children in the study.

TABLE 3.2: The relationship of the offender to the sexually abused children in the research sample (n = 93)

Relationship to abused child	n	%
Biological father	41	(32.5)
Mother’s cohabitee	15	(10.3)
Stepfather	13	(9.5)
Foster father	1	(0.8)
Brother	18	(14.3)
Foster brother	4	(3.2)
Half-brother	4	(3.2)
Brother-in-law	1	(0.8)
Uncle	8	(6.3)
Mother	7	(5.6)
Grandfather	7	(5.6)
Grandmother	2	(1.6)
Grandmother’s cohabitee	2	(1.6)
Neighbour	1	(0.8)
Lodger	1	(0.8)
Child in Children’s Home	1	(0.8)
TOTAL ABUSERS	126	

TABLE 3.3: The nature of the most frequent and the most severe abuse

	Most frequent		Most ‘severe’	
	n	%	n	%
Exhibition of sex organs — no touching	0	(0)	0	(0)
Fondling, touching of sex organs, breasts, etc.	10	(10)	4	(4)
Masturbation — offender only	7	(7)	4	(4)
Mutual masturbation	4	(4)	4	(4)
Oral-genital contact	14	(14)	13	(13)
Attempted intercourse	4	(4)	7	(7)
Digital penetration	10	(10)	15	(15)
Penile penetration	42	(43)	45	(46)
Pornographic activities	2	(2)	2	(2)
Prostitution	0	(0)	1	(1)

CONCLUSION – CLINICAL AND RESEARCH COLLABORATION

The research will be completed and a final report made available towards the end of 1990. However, some interesting issues have arisen from the experience of organizing a treatment outcome study in a field of child psychiatry in which practice is still developing.

The research team of four was based at the Institute of Child Health, with daily access to the clinical team in the Hospital for Sick Children. Despite this, and a high level of good will, coordinating the work of the two teams was demanding and complicated: a formal consideration of the reasons for this has been outlined in a conference paper³. When clinicians and reseachers share access to the patient and his or her family, each needs to recognize the legitimate anxieties of the other. There were, for example, occasions when clinicians felt they would prefer a case not to be included, for fear the researchers might further distress the child or relatives.

It was found that both the choice of treatment outcome variables, and the insistence that the treatment remain unchanged for the research period inevitably affected clinical freedom. The research team's need to maximize the number of cases sometimes conflicted with the clinical team's desire to serve what they perceived as the immediate needs of the child or family. In particular, the need for random allocation to the two treatment types led to some clinicians expressing their anxieties about the short-term needs of patients being sacrificed to the long-term benefits of the research. The need for structured meetings, and detailed communication can increase the clinicians' understandable sense that the researchers are making too great demands on them. The large amount of coordination with outside bodies complicated that between the two teams.

These issues were mostly resolved as the research progressed, but it is likely that only the experience of working together can lead to totally trouble-free cooperation on such a complicated subject.

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Marjorie Smith
Project 5.93, page 115

Normal Family Behaviour and Attitudes to Sexuality

There has been a sharp increase over the last decade in the number of reported cases of child sexual abuse, but there has been little systematic research work to inform and guide developments in clinical practice. One area where there has been no systematic information to aid the clinician, is that of *normal* sexual behaviour in families. Information on how non-referred families behave in a number of areas such as nudity at home, bathing practices, touching and physical contact, and discussion of sexual matters is relevant to the appraisal of family situations where abuse is suspected. Similarly, information on the 'normal' sexual behaviour of non-referred children is relevant to the appraisal of children who are suspected, or known to have been sexually abused.

This study of family sexual behaviour and children's concepts about sex and sexuality was set up with two main aims:

- to obtain information on the development of sexual behaviour in normal children and their families, and on children's sexual knowledge;
- to assess in a standardized way how abused children differ in sexual knowledge and understanding from children who have not been abused. (This second part of the study has not yet been completed.)

The first aim involved interviewing a non-referred community group of children and their mothers, separately, in their homes. The group was randomly selected from GPs' lists in five practices in and around London, and the selection was stratified to ensure that equal numbers of boys and girls were selected, and equal numbers of children in each age-group from four to fifteen years of age. The identified children and their mothers were invited (initially by letter, but followed by a visit to explain the study) to take part in the research. Of those approached, 85 per cent agreed to be interviewed. A total of 148 families participated in this part of the research.

The mother's interview was semi-structured in format and in addition to basic demographic information it covered a wide range of topics relating to family sexual behaviour, observed sexual behaviour in children, and discussion on sexual matters between parents and children. One aspect of the interview was questions on parental nudity in front of children, parental bathing with children, and questions on

whether the child came into the parents' bed. As well as being asked about the current situation, mothers were asked about their behaviour in the past, whether this had changed, and, if so, to give reasons why. Finally, they were also asked about their *general* attitudes to behaviour in these areas.

PARENTAL NUDITY IN FRONT OF CHILDREN

In reports of current behaviour, 39 per cent of mothers (n = 58) reported that their children regularly saw both parents naked, but a substantial proportion (n = 47, 32 per cent) never saw either parent naked. Overall, 68 per cent of children see one or other parent (or both) naked. Table 3.4 shows these results by family type. Children with two biological parents were more likely to see them both naked than were children in step-parent families. The group of children who only see the opposite sex parent naked is largely accounted for by children – in this case, boys – in single parent families.

TABLE 3.4: Children seeing parents naked (by marital status)

Child sees:	Both biological Parents		Step Parent		Single Parent	
	n	(%)	n	(%)	n	(%)
Neither parent naked	30	(29.1)	7	(43.7)	7	(28.0)
Only same sex parent naked	10	(9.7)	7	(43.7)	8	(32.0)
Only opposite sex parent naked	7	(6.8)	0	—	10	(40.0)
Both parents naked	56	(54.4)	2	(12.5)	—	—
TOTALS	103		16		25	

There were no differences associated with the sex of the child: boys were as likely to see their parents naked as were girls. Not surprisingly, there were differences according to the age of the index child – the older the child, the less likely they were to see their parents naked. In the group of 103 intact families, nearly three-quarters of the children (72 per cent) aged between four and seven years of age saw both their parents naked, but this had dropped to a third of children aged 12–16 years. There were also differences associated with the social class of the family. Table 3.5 shows that in the group of intact families, children of

parents in non-manual occupations were twice as likely as children of parents in manual occupations, to see both parents naked.

TABLE 3.5: Children seeing parents naked (by social class)

Social classes:	I, II, III ^{nm}		III ^m , IV, V	
	n	(%)	n	(%)
Neither parent	12	(21.1)	18	(39.1)
Same sex parent only	3	(5.3)	7	(15.2)
Opposite- sex parent only	2	(3.5)	5	(10.9)
Both parents	40	(70.2)	16	(34.8)
TOTALS	57		46	

$X^2(df3) = 13.3. \quad P = 0.004$

In terms of their general attitudes to parental nudity, mothers' stated attitudes were consistent with reported behaviour. Half the mothers felt that it was all right for children of any age to see their parents naked. There were differences in stated attitudes associated with the social class of the family, which also reflected reported behaviour: twice as many (32 per cent versus 15 per cent) manual social class mothers said that they did not approve of children seeing the opposite-sex parent naked. Parents were most likely to say that a behaviour change in this area would be initiated by the child, and most cited the child's increasing modesty as the reason. For example, the parents would start covering up because they could see that the child was embarrassed to see them naked.

PARENTAL BATHING WITH CHILDREN

Six out of ten children were reported to have bathed with both parents (usually separately!) at some time in their lives, while 23 per cent had never bathed with either parent. There was a fairly sharp decrease in shared bathing with age, and for most children (70 per cent of the group who had bathed with their mothers, and 79 per cent of the group who had bathed with their fathers) it had stopped before they were aged five. All other children who were reported to have bathed with their parents had stopped doing this either long before or, in three cases, at puberty. Most mothers said that they stopped bathing for practical reasons, such as the amount of mess it made, or the size of the child. There were no significant differences in shared bathing with the sex of the child, but children of both sexes were more likely to bath with their mothers than with their fathers. Somewhat surprisingly, in the light of the family differences in parental nudity, there were no social class differences in family bathing patterns. There were, however, differences in retrospective reports, according to the age of the index child. Mothers of children in the two oldest age-groups were significantly more likely to report that neither parent had ever bathed with the child, than mothers of children in the youngest age-group. This may simply

be because parents forget what they do — parents of older children have to think back further. As this difference was not found in other areas where mothers were asked to report retrospectively, it may indicate a real change in behaviour over the last decade.

In some respects, mothers' attitudes in this area did not reflect their behaviour. Although a minority of mothers felt that shared bathing was inappropriate at any age, between 46 and 59 per cent said that it was all right during the pre-pubertal years. In contrast to the practical reasons that had most often been the stated cause of the actual behaviour change, a third of mothers said that behaviour change would be brought about because of the child's increasing sexual curiosity, while a further third said that the child's modesty would be the reason.

Although there were no social class differences in reported behaviour, there were in attitudes: in manual social class families, mothers were more likely to think it inappropriate for fathers to bath with their daughters at any age, and to think that shared bathing should stop before the child was aged five. They were also more likely to say that shared bathing would stop because of the child's sexual curiosity.

It seems that although many mothers would not think it wrong to bath with their children up to puberty or beyond, in most cases practical reasons determine that behaviour change takes place before this.

COMING INTO THE PARENTS' BED

Most children (67 per cent) are reported to have come into their parents' bed at least weekly, at some point in their lives. There were no sex differences, and as table 3.6 shows, no differences between intact families, and reconstituted or single parent families. Children were less likely to come into their parents' bed as they get older. Approximately a third (35 per cent) said that behaviour change had been initiated by the child, but another third said that the change had been initiated by the parents, and mothers gave reasons such as wanting more privacy.

TABLE 3.6: How often children came into the parental bed (ever)

	All children		Intact families	
	n	(%)	n	(%)
Nearly every night	51	(35.7)	36	(35.0)
At least weekly	48	(33.6)	37	(35.9)
In special circumstances only	20	(14.0)	13	(12.9)
Rarely	14	(9.8)	10	(9.7)
Never	10	(6.9)	7	(6.8)
TOTALS	143		103	

Of course, not all the children who come into their parents' bed stay there all night, or go to sleep there: only 5 per cent of children in intact families, but 16 per

cent of children in single parent families, slept all night in their parents' bed. Many children came into their parents' bed only in the mornings. There were social class differences in this behaviour, and parents' attitudes, which mothers often described as 'rules', reflected this. More mothers in non-manual families said that they had a rule that children could only come into their bed in the mornings, while mothers in manual social class families more often said that they only let their children into their bed if the children could not get to sleep or woke in the night.

CONCLUSIONS

Parental/child behaviours in the three different areas were quite strongly associated, and mothers' reports of whether the parents are seen naked by their children were a good indicator to the other behaviours

in the past. That is, families who currently let their children see then naked were likely to have bathed with their children, and to have let their children come into the parents' bed, either now or in the past.

Overall, we found that in these three aspects of behaviour there were very few differences according to the sex of the child. Parental nudity, shared bathing, and coming into the parents' bed decreases with the age of the child, and most often the initiative for change is seen as coming from the child. Mothers' reports of behaviour in the family and their attitudes were very much in line, and in general these also reflected the social class differences in reported behaviour.

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Mervyn Murch
Project 5.85, page 113

Research Spin-Off and the Children Act 1989

INTRODUCTION

A study to examine the processes by which children are represented in court proceedings, carried out by the Socio-Legal Centre for Family Studies at the University of Bristol, was commissioned by the Department of Health in 1985. It has produced a number of unexpected 'spin-off' findings; that is, information which was not specifically concerned with the processes of child representation. This information was largely concerned with the length of care proceedings.

The findings also had important implications for the ways in which courts control their child-related workloads; in particular, underlining the crucial importance of an effective management information system. Throughout the study, there was close liaison between the researchers and an advisory committee, including members of the Child Care Law Review, which prepared much of the new legislation. As a consequence, a number of provisions in the new Children Act 1989 are designed to avoid unnecessary delay in proceedings and to improve the flow of information concerning the courts¹ handling of child-related proceedings.

THE LENGTH OF CARE PROCEEDINGS AND THE PROBLEM OF AVOIDABLE DELAY

The longer it takes to complete care proceedings, the greater the risk that children will be unsettled by the associated uncertainties and delays. Children subject to a series of interim care orders while their case is being determined can experience a number of short-term care arrangements, which can involve being shunted from one short-stay home to another. Because interim care is often regarded as temporary, a child may be cast into a virtual state of limbo, and contingency plans by the local authority either simply not made, or made in times of crisis without proper planning¹. Moreover, the longer the child's absence from home, the more the chances of successful rehabilitation diminish².

From the parents' point of view, not only can 'justice delayed' appear to be 'justice denied', but prolonged care proceedings can greatly increase family tension. The Cleveland Child Sex Abuse Inquiry drew public attention to a

'chilling picture of children being removed abruptly from their homes, frightened, distressed, and uncomprehending, with parents desperate at the discovery of how few rights they have over their children once the state has intervened' (Guardian, 5 July 1988, page 16).

Parental separation from very young children, a sizeable majority of whom are destined to return home after they have been in interim care, can seriously impair family bonding and lead to later behavioural problems. Yet grossly deficient court-based management information concerning the family jurisdictions means that it is not possible to quantify, on a regular basis, the nationwide extent of delay in juvenile care courts, nor in most other child-related civil proceedings.

BACKGROUND TO THE RESEARCH

The initial impetus for the study arose from the Department of Health's responsibilities under Section 105 of the Children Act 1975 to monitor and report to Parliament on the workings of that Act. Its primary purpose was to study those provisions, only fully implemented in May 1984, which permitted Juvenile Care Courts to order that parents and children be separately represented if there appeared to be a conflict of interest between them. These arrangements included the establishment of special panels of guardians *ad litem*, administered by local authorities to safeguard the interests of the child. Members of these panels, all experienced in child care, were to work closely with specialist children's lawyers from panels organized by the Law Society. The primary objective of the study was therefore to examine the workings of the new system.

The research 'spin-off' arose in the following way: the main study was conducted in ten Juvenile Care Courts (three in the North East and seven in the South West region). In order to select a reasonable representative sample of care cases, it was necessary first to estimate the size of court workload by examining brief details of the cases contained in court registers. Data were collected in 1,916 civil care cases, covering a three-year period up to 31 May 1986. In order to examine closely the processes of child representation

as it worked in practice, it was also necessary to examine their court files in detail, and to observe court hearings. Whenever possible, the parties to the proceedings and the practitioners (lawyers and social workers) who acted as representatives in the case were interviewed, so that their experience and opinions could be taken into account.

Overall, a total of 802 court hearings were observed, comprising 529 interim hearings, 216 full hearings and 57 part-full hearings – that is, final hearings which lasted longer than one day. From these cases, a sub-sample of 87 was drawn for intensive follow-up study.

THE SPIN-OFF

The 'spin-off' information about the length of care proceedings was drawn primarily from registers and from the extensive observation of hearings in the ten courts. The principal findings were:

- Over the three years, cases took *increasingly longer to complete*. For all types of civil care case, the mean number of weeks rose from 3.8 weeks in the first year, to 7 weeks in the third. Neglect and ill-treatment cases involving mainly children under five took on average 6.5 weeks to complete in their first year and nearly 10 weeks in the third.
- The *younger the child, the longer it took to complete the case*. Cases involving children under 10 were three times as likely to take three months or more to complete than those where they were over 10.
- Courts *vary* considerably in the length of time they take to complete cases of similar kinds.
- The number of *interim hearings* and number of *interim care orders* per case increased steadily over the three years. The proportion of cases taking more than eight weeks to reach final order increased from 30 per cent in the first year to over 55 per cent in the third. In the third year, over half the cases involved three or more hearings, compared with less than a third in the first year.

Observation of hearings in court indicated that there were a number of reasons why care cases often took so long to complete, and why the position seemed to have deteriorated after the provisions for separate representation were fully implemented in 1984. Some of the reasons were within the courts' control, others not. Those outside the courts' control included:

- poor liaison between the parties to the case;
- the time needed to allow parents to be represented;
- the time needed by the local authority to evaluate the child and family and to prepare its case;
- the availability of guardians *ad litem* to prepare reports; and
- problems relating to the availability of expert witnesses, particularly expert medical practitioners.

Among the factors which were within the courts' control, the most serious were as follows:

- poor listing arrangements, with some courts apparently pursuing a policy of deliberate over-scheduling;
- weak control over the pace of the proceedings;
- a reluctance to resist application for adjournments and a local culture of acceptable delay;
- resource problems, such as the availability of magistrates, court rooms and staff; and
- certain procedural problems such as the need to hold an interim hearing when all parties were agreed on the need for a further interim order.

THE CHILDREN ACT 1989

Reducing delay in children's cases

How does the Children Act 1989 seek to reduce the risk of delay? firstly, in Section 1 (2), it establishes the general principle that delay in determining a question which relates to the upbringing of a child is likely to prejudice his or her welfare. This is designed to encourage courts to reduce the delay in children's cases. Secondly, in parts II and IV of the Act, the court is required to draw up a timetable for the case to avoid delay, and may, (under Section 11(1) and Section 32) give directions to ensure that the timetable is maintained. In addition, rules are being framed which will reinforce these provisions – for example, by specifying periods within which certain steps must be taken – which empower the court to control the duration of proceedings.

Improved management information concerning children's cases

These new provisions will therefore require courts to control the management of child-related proceedings more actively than they have in the past. The lack of detailed management information collected by Magistrates' Courts led the researchers to recommend ways in which the collection of information concerning the courts' handling of child-related proceedings could be improved. Section 83 (6) of the Children Act 1989 contains a provision that the Secretary of State should lay before Parliament an annual consolidated and classified abstract of information concerning these matters. The Secretary of State also has power to direct the Clerks of each Magistrates' Court to transmit such particulars as may be required concerning the court's child-related workload.

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Family Support and Prevention: Studies in Local Areas

INTRODUCTION

Public concern remains high over the situation of children who are at risk of harm in their own homes, or deprived of the necessities for normal development, or are handicapped in some other way. Statistics on the extent of these problems have only recently become available: they suggest that, nationally, between three and four children in every thousand meet official criteria for being placed on a child protection register, and that the trend may be upwards¹.

Although inter-agency collaboration is essential, local authority Social Services Departments (SSDs) have a central responsibility for the well-being of children in need. Broadly speaking, SSDs may carry out this responsibility by removing children from dangerous or neglectful home environments (with the authority of a court); or by providing preventive services to children in their own homes. In recent years, fewer children have been removed from their parents into local authority care — partly in response to research evidence which highlighted the disadvantages of the care system². Since there appears to be no decrease in the numbers of children in need of help, higher priority has to be given to the development of preventive services for families in difficulties, and to research into their effectiveness.

THE NISW RESEARCH PROJECT

The Children Act 1989 places a general duty on local authorities to safeguard and promote the welfare of children in their area who are in need; and to promote the upbringing of such children by their own families wherever possible, through the provision of family support. The Family Support research at the National Institute for Social Work (NISW) Research Unit was intended to describe the demands placed on SSDs in two English areas by children and families in need of supportive services; the availability of voluntary and informal family support resources — how they had developed and how they were used; and whether the availability of voluntary projects made any difference to social work practice and to the outcomes of family problems. In one of the research areas ('Newpath'), voluntary resources were highly developed, while in the other ('Oldweigh'), which was very similar in

population structure, there was less emphasis on community development and the voluntary sector.

In community care, local authorities are on the threshold of a new era: they will be expected to commission services from a variety of providers for different kinds of vulnerable people, rather than provide such services from a more or less monopolistic position themselves. The role of local authority social workers in community care is also changing, with more emphasis beginning to be placed on assessment and case management than on casework in the traditional sense. Social workers will need to become expert in putting together individually-tailored packages of support, coordinating help from different sources and monitoring results with clients and employers. These changes will also influence social work practice with children and families. 'Oldweigh' did not have policies which emphasized the development of a variety of locally-based resources outside the direct control of the SSD. 'Newpath', on the other hand, had for some years been implementing policies of this kind, and so might provide a good context for observing the development of social work roles, and the ways in which a network of local resources might benefit families under stress.

The researchers studied the development and operation of seven new family projects in 'Newpath', through interviews with organizers and local managers, and observation of activities. A random sample of young families in local areas surrounding the projects was interviewed to assess how widely they were known, and whether they could attract the families with most needs. Unselected families referred to the SSDs in 'Oldweigh' and 'Newpath' were interviewed at the time of referral, and activity of social workers in providing services and linking families to resources was monitored. Parents were re-interviewed after four months to assess changes in family problems.

RESULTS

There was evidence that the new family projects were gradually establishing themselves and becoming well-known in their own areas. They had strengthened local resources on relatively disadvantaged housing estates, by providing new activities and advice points, by drawing in new volunteers, and by opening up

new opportunities for local mothers of young children. They succeeded in attracting a higher proportion of the families with the greatest needs, without excluding other families.

There were marked differences in composition and in material needs between the randomly-selected families in the 'Newpath' population and the families referred to the SSDs in the two research areas. Half the referred families were headed by lone parents, who were usually divorced women in their late twenties or thirties. Many more of the referred families — couples as well as lone parents — were disadvantaged in housing and in access to employment and consumer goods. A high proportion of the randomly-selected 'Newpath' community families believed the SSD was essentially a financial relief agency. Similarly, in both referred samples, material problems were the commonest reason for contact with social services, and financial help or advice the most often expressed expectation. Many clients in financial difficulties appeared to be turning to the SSD, either as a first port of call, or after being turned away by Social Security offices.

There was no evidence that the social workers in 'Newpath' were responding in different ways from those in 'Oldweigh', in spite of the availability of local, specialist advice services in the new family projects.

Compared with the randomly-chosen 'Newpath' families, the main parent in the referred families was much more likely to be suffering from feelings of depression, and to describe a range of severe family problems to do with relationships and health as well as money. These referred parents felt more isolated from sources of community support, although the actual number of available supporters was similar, and they were more likely to be in conflict with others, especially close family members. However, a sizeable proportion of referred families appeared to have only financial problems. It was difficult for social workers to carry out more than superficial assessments, and any help offered usually consisted of a brief contact, often for an administrative purpose. To do more than this, the departments would have had to move to a more

controlled and selective form of practice. There was no evidence that the new family projects in 'Newpath' were as yet being used systematically to relieve the pressures on the SSD, or that social workers were developing new forms of practice. However, four to five months after referral, parents in 'Newpath' reported more improvement in family problems, and showed more change on a standard measure of emotional distress, than did those in 'Oldweigh'.

CONCLUSIONS

Two types of so-called preventive provision need to be distinguished. Specific provision — intended, for example, to prevent the need for entry to care — is selective, aimed at families with already-identified special needs and severe problems. In the future, local authorities are likely to retain direct responsibility for specific prevention, either by providing special services selectively themselves, or by commissioning others to provide them. However, local authorities also have a duty to promote the welfare of children more broadly, through the provision of family support. The results of the research supported the view that this second type of provision can be made through independently-run voluntary and informal groups, based in neighbourhoods with many social needs. Within this kind of strategy, a number of differently organized, or relatively unorganized, groups would be involved in the provision of family support in a social services area. This could only be achieved through funding policies which provided more security to local groups, in exchange for better accountability.

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Project 5.78, page 112

Leaving Care for Independence

Each year thousands of young people are officially discharged to 'independence' from the care and responsibility of their local authority 'parents'. For most of these young people this change will have been automatically effected upon reaching their eighteenth birthdays, regardless of how willing or able they were to leave care and cope with independent adult life.

Until fairly recently, little more was ever heard about this group. With the exception of a few personal accounts and descriptive studies, information about their experiences of leaving care and what happened to them once they were officially discharged was scarce. In the last ten years, however, there has been increasing public concern and with it a growing awareness about the sorts of problems some of these young people face.

During this time, a number of important, albeit small-scale, research studies have been conducted. Although these studies are not strictly comparable in terms of their design, timing and coverage — for example, some include young people leaving foster home placements, whilst others focus on those leaving residential care — a major strength of their findings is that they are based on young people's own accounts of their experiences. Put together, they present a consistently depressing picture of young people leaving the care system socially and culturally isolated, poorly educated and vulnerable to periods of unemployment, poverty and homelessness¹.

However, in spite of these concerns, there is still relatively little basic data available on this group. For instance, beyond the numbers who graduate out of the care system each year at 18 or 19 years of age (6,963 according to the most recent (1987) figures for England and Wales), there are no national statistics on these young people: on how long they have been in care, where they are placed or how long they remain there once they are discharged. It is not clear what proportion of this group experiences leaving care simply as a change in legal status with no accompanying moves or changes in living arrangements — those who remain living with their foster families, for example — and for how many it involves both. We do not know how many young people currently make use of social work services after they have left care or how many might potentially benefit from it. In view of the new duties and responsibilities which the Children Act 1989 will impose upon local authorities with regard to the

preparation and aftercare of these young people, it seemed important to find out more about the sort of tasks that were facing them.

The purpose of this study was to complement some of the earlier research findings by providing some basic up-to-date information on young people's care backgrounds and post-care contact with social services. It was designed to build on a recent Department of Health survey of child care placements which provided us with a ready-made cohort of young people who had been discharged at 16+ years of age from the care of a number of different local authorities². However, by the time this survey had been completed, some of these young people had been out of care for up to two-and-a-half years. Finding these young people, while technically possible, would have been an extremely costly and time-consuming affair. This meant setting very modest objectives and restricting ourselves to information which could be collected quickly from social workers, records and files.

The findings that follow are based on information gathered on 135 young people who graduated out of the care system between April 1986 and March 1987 in three different local authorities; a county, an inner London borough and a northern city.

CARE CAREERS

One of the most striking findings was the amount of movement experienced by these young people, particularly in the run-up to their discharge from care. Indeed, it seemed that unless a young person was firmly established in a long-term foster home by their mid-teens, the chances of their experiencing at least two placement changes, including a breakdown in their final two years in care, was very high. Only one in five of our group could be said to have enjoyed a long-term placement for the duration of their stay in care. These were young people who had been admitted to care in their pre- and primary school years and who had spent most, if not all, of their time in care either with the same foster family, or in a residential group home.

Not surprisingly, it was the older, more recently admitted youngsters who moved most often, reflecting the difficulties that social workers face in successfully placing these older children. Nearly 60 per cent of our group had been admitted in their secondary

school years, the most common age of entry being 15. Of these, more than half had experienced three or more placements during their short spells in care, while a further 10 per cent had experienced five or more placement changes.

However, placement change and disruption was not confined to these older care-entrants. The remaining 20 per cent of our group, who had been admitted in their pre- and primary school years, had also experienced unsettled periods in care. Apart from two youngsters whose long-term foster homes had broken down in their seventeenth year, all of them had moved into new placements in their early to mid-teens and had experienced at least one other placement change in the two years prior to their formal discharge.

Some of these changes were necessary because of the ‘staged’ nature of much of these authorities’ teenage placements. In our London authority, for example, it was common for young people to move from a community home at 16 to a supervised bedsit, from where they would move directly into their own flats, usually at 17 years of age. In the county, young people in specialist foster homes would commonly move into their own digs at 17. However, a large proportion of these new placements were not planned and came about either as a result of placement breakdown or because of the unsuitability of their move-on accommodation.

FINAL PLACEMENTS

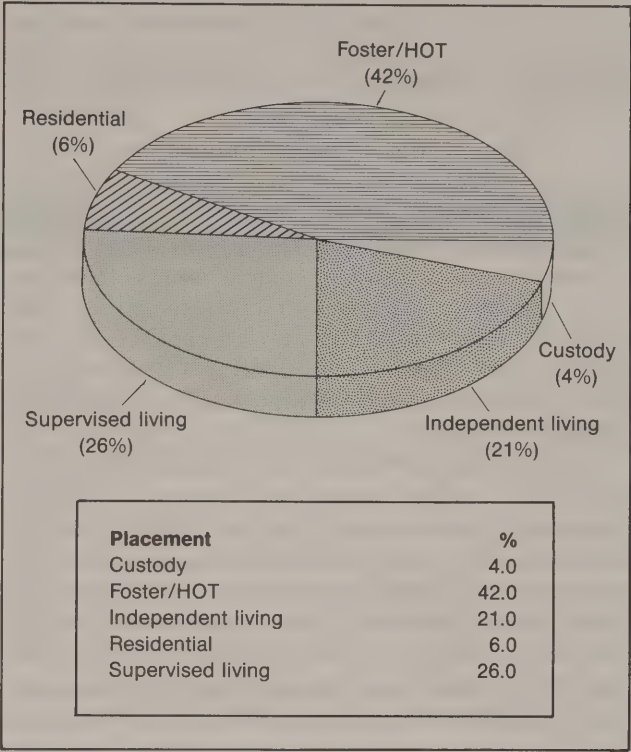
While few of our young people were technically discharged from care before their eighteenth birthdays – only 14 per cent were aged 16 or 17 years – many more had effectively ‘left’ care much earlier than this and were already living in their own accommodation by the time they reached 18. As figure 3.1 shows, nearly half were already living in some form of independent accommodation by the time they left care, such as flats, lodgings, half-way houses, hostels, and so on. Moreover, of the one in three care-leavers who were still living in foster or residential care settings at the time of their official discharge, more than a third were not expected to remain there for very long.

EDUCATION AND EMPLOYMENT

Although the issue of preparation for independence was not examined in this study, our findings on young people’s educational and employment status showed that few had many of the material means required for self-sufficiency. More than three-quarters of our group left care with no educational qualifications and were either unemployed at the time of their discharge or engaged in low-paid and low-status occupations.

However, it would be unwise to draw any general conclusions about the effects of care on young people’s schooling from such crude data, as other young people from similarly disadvantaged backgrounds, but who have not been in care, may perform

Figure 3.1: Final Placements of the Leaving Care Cohort Prior to Discharge



Source: Project data

equally badly at school³. Nevertheless, it would seem that the educational and career development of young people in care is accorded a relatively low priority. One in five of the social workers involved in the study either did not know whether their young people had any formal educational or vocational qualifications or had not thought to record this on file.

LEAVING-CARE PLANS

Another issue which this survey has raised, along with other recent studies, is the lack of any formal planning at the time of the young people’s discharge from care. Compared with the admission process, leaving care seems to be a relatively *ad hoc* affair, involving little social work input. Many young people had only minimal contact with their social workers in the period prior to their discharge, while others seemed to have no worker assigned to them at all. Where leaving-care plans had been made, these were generally with a view to short-term goals and seemed to consist of little more than finding alternative and often temporary accommodation from which the young people could officially leave care.

AFTERCARE AND ASSISTANCE

finally, there is the question of what sort of support and assistance the young people received from social services once they left care. Not one of our authorities had developed formal plans for the aftercare of these young people. There were no leaving-care budgets,

and few if any written guidelines on what sort of assistance social workers could offer. About half of our care-leavers received no financial assistance at all, and of those who did, sums varied between £40 and £600, depending on how generous the local authority was and how well-informed social workers were of the relevant powers at their disposal.

In each of the three authorities, the task of providing aftercare was said to be the responsibility of individual field workers and residential staff and, where appropriate, of foster parents; but there were no specific policy guidelines on what this 'aftercare' might comprise. This meant that any support the young people received was dependent on the discretion of individual workers, and the amount of time that they felt able to allocate to this task on top of other heavy duties.

For two out of three young people in our group, there were no firm plans to continue social work contact once they left care. The most common arrangement was that young people could come back at their own initiative, if and when they needed help. Of these, a third did seek further help, most within 12 months of leaving care: in the majority of cases this was for practical and financial advice, connected mainly with housing and benefit problems. Most were dealt with on a one-off basis and were often referred to other workers or agencies. Only half were dealt with by their original social worker.

CONCLUSION

Although we cannot be certain of how typical our three study authorities are, they do illustrate how varied a group young people leaving care may be. Local authorities may therefore have to develop a broad range of resources in order to meet their varying needs. They also demonstrate just how basic services currently are within some local authority departments. Imposing new duties without a parallel increase in resources may therefore do little to improve the situation of many young people leaving care.

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Relatives: A Neglected Group of Carers

Our research into the use of custodianship in its first three years has shown that it was mainly used by relatives looking after children who were not in care¹. Before the implementation of Part II of the Children Act 1975, at the end of 1985, it was thought that the provisions would be used mainly by foster carers.

Custodianship was a new kind of legal custody available to people who were looking after other people's children. It was based on recommendations of the Houghton-Stockdale Report in 1972, that there was a need for an alternative to adoption for relatives and foster parents of children in long-term placements where family links remained significant or adoption was ruled out by financial considerations.

THE STUDY

The study involved an analysis of all custodianship applications that were in progress during 1988 in four local authority areas: 38 of the 54 applicants were interviewed, in cases involving 64 children, and 49 of the 51 social workers who prepared the reports for the court. Largely because of the delays experienced in many of the cases, it was possible to interview only a small minority of the birth parents and older children. This inevitably means that the picture of the experience of custodianship drawn by the study is less complete than we would like it to be. In most cases, the views of the birth parents could only be derived from the accounts of the social workers or the applicants. Younger children were often present during the interviews and often made spontaneous comments or were asked to comment or confirm a detail by the applicants. We were therefore able to learn something of their views and to observe for ourselves the way they took their place in the family setting.

THE FAMILIES

The largest group of applicants were grandparents, applying for young children who had been living with them for all or most of their lives. The mothers themselves were likely either to have been in their teens at the time of their child's birth, or to be in their early twenties and to be described as 'immature' either by their parents or the social workers; those who were interviewed also had that perception of themselves.

In the majority of such cases, the reason for the application was the grandparents' desire to safeguard the children's place with them, to be given a clear legal right to make the normal day-to-day decisions about their upbringing and to symbolize the child's place in the family.

In the cases involving relatives generally, it appeared that the need for such an order arose most often in situations where there had been a substantial degree of agreement by the parents to the placement, but also an element of uncertainty about its stability or about the formal powers of the carers to make day-to-day decisions about the children's care. In some cases, the uncertainty was not a result of any sense of potential conflict with parents, but because of a discovery that only a formal endorsement of the placement could convey the necessary powers: the most frequently mentioned was that of consenting to medical treatment. In some cases, there had been a background of concern about the children's well-being while they were living with their parents; and in a smaller number of cases, the children had come into the grandparents' care from that of a local authority social services department following physical or sexual abuse.

A number of the grandparents and other relatives looking after children who had been in care, or for whom the alternative would have been care, told us that they took on the care of the children because they could not bear to think of them going to live with strangers. In the words of one grandmother caring for three children:

'I suppose the feelings were strong, and I didn't want to face [the prospect of not seeing them] so I asked if I could have them . . . A lot of the people I spoke to agreed with me, that children are better with their family in circumstances like that . . . I think that's true. I think at least they'll have some identity.'

The circumstances in which the children came into the care of the unrelated foster carers had features in common with those where relatives were caring for children following bereavement or marital breakdown, or where the children had suffered or had been at risk of neglect or abuse. There was a blurring of the distinction between foster carer and relative

applicants, because in some cases the children had been boarded-out with the relatives while in the care of the local authority prior to the custodianship application.

Where there was less than clear agreement to the order, applications were mostly withdrawn or allowed to lapse. We only found two applications in which the social worker had not felt able to recommend that the Custodianship Order should be granted and only one where the application was contested in the court by a parent. In none of these three cases was a Custodianship Order made, although the children remained with their grandparents in two of them.

NUMBERS OF ORDERS

In the main study, 56 Custodianship Orders were made, including two in adoption proceedings. None of these cases was contested. Of the remaining eight custodianship applications, all by private applicants, four were withdrawn or allowed to lapse and four were not completed before the end of the study. Generally, access and maintenance were not at issue and only three supervision orders were made. We found two applications to revoke a Custodianship Order which were not included among the 64 main study cases; one was granted and one refused.

Custodianship allowances were being paid in respect of almost all children who had previously been in care, usually at the basic rate for boarding-out allowances. No custodianship allowance was being paid in respect of any child who had not previously been in care.

A postal survey of all social services departments in England and Wales obtained a response rate of 50 per cent. The results suggested that the main study areas were not untypical in terms of the rate of children leaving care on Custodianship Orders as a percentage of children boarded-out in each authority. It is clear that private applications were in a majority and that custodianship did not offer a route out of care for any significant proportion of children in 1988, in any area for which we have information. (The proportion was less than 1 per cent in most of the responding authorities with a mean of 0.6 per cent. The proportion in the main study data ranged from 0 to 1.7 per cent.)

WAS CUSTODIANSHIP WORTH HAVING?

We saw much evidence that the children were greatly loved and that the carers' concern for their welfare went well beyond provision for their physical well-being. Some carers, often relatives who made private applications and received no allowances, were prepared to suffer considerable financial loss and sometimes even hardship.

The applicants we interviewed, and particularly the relatives, clearly considered it an advantage that such a provision existed, even if they were sometimes critical of the length of time it took to obtain an order, and of some of the features of the pre-hearing stage,

the court attendance or the court hearing itself. Only in five cases was any dissatisfaction expressed with custodianship. There was almost always continuing parental or wider family contact. Where there was no contact, the children were aware of belonging to a different family from that of their carers.

Having examined the figures published by the Lord Chancellor's Department and the Home Office, and amended them from our own researches, we estimate that between 1,000 and 2,000 children were made more secure by custodianship, in the families that were caring for them, in the three years from the end of 1985 to the end of 1988. If these cases resembled those included in our study, we consider that there was and will continue to be a need for some provision such as custodianship. For some of the families in the study, it would have been helpful if it had been available earlier.

RELATIVES AS CARERS

The research has provided some useful glimpses of a group of families who have been neglected by past child care research studies — partly, of course, because of the difficulty in finding them. In our view, the private carers, mostly grandparents, who applied for custodianship represent only a small minority of such placements. There are two reasons for thinking this: firstly, most of these families were in fact in contact with the social services department and therefore more likely to hear about custodianship; and secondly, the placements had started informally and by agreement, and might have continued on that basis if there had not been some particular reason to seek a legal Order.

The private carers we interviewed had very interesting things to say about the circumstances in which these family placements are made, the carers' motivation for taking on responsibility for the child and the often complicated relationships between all the people involved. On the basis of this, and other research, it seems likely that a substantial number of children who are not in care now live with carers who are not their parents, and that in future the number is likely to grow as the rates of family breakdown and of births outside marriage increase. Against this background and given the abolition of custodianship and the introduction of Residence Orders by the Children Act 1989, placements like these, and the factors which contribute to their success or failure, deserve further study.

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The Day Care Project

In the last few years, mothers' employment and children's day care have become a subject of political, economic and social debate to an extent unparalleled since the War. In 1982, the Department of Health funded the Thomas Coram Research Unit to undertake a major study of these issues, at a time when their importance was largely unrecognized. The study focused on two-parent households where the mother resumed full-time employment after taking maternity leave to have a first child, and where the children began full-time day care before nine months of age.

THE DESIGN OF THE STUDY

Mothers were seen on four occasions – at 5, 11, 18 and 36 months after birth; children on three occasions – at 5, 18 and 36 months; and non-parental carers twice, when children were 18 and 36 months. A variety of methods were used in order to achieve a complete picture of children, mothers, households and day care settings. These included interviews with mothers and carers, observations of children in their main day care environments, assessments of different aspects of children's development and the completion by mothers of diaries of their child's week and schedules about their child's temperament.

The original intention had been to use a sample of 240 mothers and children. Of these, 180 were to be 'returners', divided into three groups of 60, using different types of day care – nurseries, childminders and relatives – while a further group of 60 would be 'non-returners'. Each sub-group of 60 was to be divided equally between women in high-status jobs (essentially professional and managerial), and women in lower-status jobs (clerical, sales and manual). However, our intention to create a 'neat' sample, with balanced sub-groups, was defeated by what we found in real life. At that time, there were very few private nurseries taking babies with employed parents – with the result that our nursery group comprised only 36 children, most of them with high-status mothers. The relative group, on the other hand, involved mostly lower-status mothers, reflecting the different types of day care used by different social groups.

As time went on, the original, 'tidy' design had to be further modified. Many women who resumed full-time employment before their child was nine months old (39 per cent) did not remain in full-time

employment until their child's third birthday, but had periods of working part-time or not being employed at all. Day care arrangements changed: nearly half the children (45 per cent) had at least one change of placement while their mothers were in full-time employment, with a quarter moving from one type of care to another – for instance, from a relative to a childminder. By the time the children were three years old, not only were fewer women in full-time employment (107 compared to 184 who returned after maternity leave), but the distribution of children between different types of day care had changed. The proportion with childminders and relatives had fallen, while the proportion at nurseries and with 'others' (mainly nannies) had increased.

These changes – although frustrating from the point of view of research design – reflect how things are in the real world and are also important data in their own right. Many mothers do drop out of full-time employment, many children do experience changes in day care; and the study is able to throw light on the nature and reasons for both sets of changes. There were few changes, however, in the membership of the sample. We began with 255 mothers and children, and still had 243 after four contacts, when children were three years old. This very low attrition rate is a reflection of the high level of cooperation we received.

Fieldwork for the study began in 1983 and ended in 1987. The Department of Health, however, funded a follow-up study, which enabled return visits to mothers and children to be made when children reached six years of age, and had started at primary school. The fieldwork for this follow-up ended in May 1990, and the results will be available in 1991.

THE EFFECTS OF DAY CARE ON CHILDREN

The study has been an ambitious and unique undertaking, and has produced material on a wide range of issues. It provides an insight into the operation of dual-earner households during early parenthood, and the experiences of women as paid workers and mothers. More specifically, there is material on the decision to resume employment after maternity leave; making day care arrangements; women's employment histories after childbirth, and occupational mobility; the meaning of employment to women and

the experience of motherhood; the physical and psychological well-being of women; fathers' employment and occupational mobility; how parents manage the dual-earner lifestyle; social networks and the availability of social support¹.

But here, we want to concentrate on the child data, and on two questions in particular: what effect did day care attendance have on the children, and what difference did the type of day care make? (A more comprehensive answer to these questions is included in other publications by members of the research team².) As a starting point, we assessed children at five months, before most had experienced day care. At this point, there were no significant differences between the four sub-groups (the 'non-returners', and the three types of day care within the 'returner' group) in developmental status, temperament or mother-infant interactions.

Subsequently, some differences did emerge, and these remained significant after we had allowed for factors such as initial developmental status, mother's educational level and child's gender. The differences were for *type of day care*, not for day care in general, and did not cover all aspects of development. For example, intellectual (cognitive) development showed no effects of day care at either 18 or 36 months.

For language development, however, there was a negative effect — but only for one day care sub-group. There was some indication that the nursery sub-group, on average, fared less well in language development. At 18 months, these children were less likely to have many word combinations, while at 36 months they performed less well on another language development task, naming vocabulary. For socio-emotional development, there were also day care effects, but these were more diverse. At 18 months, the nursery sub-group were less concerned on meeting an unfamiliar person, probably reflecting greater experience with different people. They were, however, the group that showed most concern on being temporarily separated from their mothers, during a stranger approach-separation-reunion sequence built in to the home visit. On the other hand, responses upon reunion did not differ, and it is this response which is considered most important in assessing attachment.

At three years, there were no differences in behaviour problems, but there were some indications of day care effects on social development. Day care experience was associated with less timidity and more sociability towards the observer, more cooperation and a more positive mood. Within the day care group, children in the nursery sub-group showed higher levels of positive sociability — behaviour such as sharing, cooperation and empathy with other children.

Overall, then, the study shows little evidence of any *overall day care effect*; there is nothing to show that non-parental care is, *per se*, damaging and indeed there are some positive aspects in social development at age three. Our data cannot contribute to the current

American debate about whether or not full-time day care before the age of 12 months may increase the likelihood of insecure attachment, since our measures of socio-emotional development did not include the standard measure for attachment used in the American research. We shall be focusing on this in the six-year follow-up study, and hope to be able to draw some more specific conclusions from that work.

TYPE OF DAY CARE

What does emerge, however, is a *type of day care effect* with the nursery group displaying some positive effects in social development at three years, but some evidence of adverse effects on language at 18 and 36 months. Does this mean that very young children needing day care will do better if they are not placed in nurseries? To answer this question, it is necessary to look further at the nurseries in our sample.

We drew children from 33 private nurseries spread throughout the Greater London area. Two-thirds were workplace attached, many to hospitals, schools and colleges. Conditions varied considerably, but most were very isolated and many were under-resourced, which was reflected in poor staff-child ratios, problems with accommodation, poor pay and conditions, and instability of care-givers for children. Observations of the children in different settings showed that for measures of affection, communication and responsiveness — all shown to be important in the literature on adult-child interactions — the home and relative group of children scored higher than the child-minded group, which in turn scored better than the nursery group. If communication (received by the child) and responsiveness (to the child's communications) are taken into account, the nursery effect on language disappears. This suggests that what is important is not *nursery care as such*, but the *quality of care* within the nursery.

Our interpretation is that effects resulting from type and quality of care are mixed in our results, and that the evidence on language reflects more on the variable quality of private nurseries at the time our study was undertaken than on the inherent unsuitability of nursery care for young children. This conclusion is reinforced by experience from Sweden, a country with a system of well-funded, high quality nurseries, where there is no evidence of adverse effects resulting from nursery care.

In the present situation of rapid growth in nursery care for young children, the results of our study emphasize the need to pay attention to quality, and particularly the development of language-enhancing environments with high levels of communication and responsiveness. This is especially important for children under three years who are at a critical stage in the development of language; and this, in turn, has implications for training and staff levels, and hence for resources. Good quality nursery care — like any form of good quality care — is likely to be expensive, and involves paying careful attention to creating and

maintaining an environment that meets the need of young children at an important phase in their development.

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Anthony Bottoms and William McWilliams
Project 5.87, page 114

Evaluating Intermediate Treatment

In 1983, the then Department of Health and Social Security commissioned a major research project into Intermediate Treatment, located at the University of Cambridge. The research began in 1984 and will be concluded in 1990.

The term 'Intermediate Treatment' (IT) is not widely understood outside specialist juvenile justice and social work circles. It came into use at the time of the Children and Young Persons Act 1969, and was intended to refer to a wide variety of activities with children and young persons, but to exclude institutional placements at one end of the spectrum, and simple one-to-one casework at the other. Target populations for IT could include:

- offenders or non-offenders attending IT programmes as a requirement of a Supervision Order;
- offenders attending on a legally voluntary basis; and
- non-offenders attending voluntarily.

Activities undertaken within IT programmes have varied greatly — from specialist offence-oriented programmes for persistent or serious offenders (the 'heavy end', as it is known); through motorcycle activity groups, life and social skills programmes, voluntary community service or similar activities; to such things as 'providing opportunities for individual counselling and informal group discussion in a recreational setting [and] encouraging staff-child relationship building'.

To add to the complexity, in many local areas responsibility for IT is shared between Social Services Departments (SSDs) and the probation service, and there is often some input from the voluntary sector as well. Moreover, in many, if not most, areas there have been radical changes in IT policy or management, or both, during the 1980s. It is fair to say that most areas during this time have increasingly separated their provision for offenders from that for non-offenders; and increasingly concentrated their main attention on IT as an alternative to custody for 'heavy end' offenders¹.

Researching into such a diverse and complex social activity, aimed at different target groups, and changing rapidly over time, is not an easy task. The Cambridge team, with the agreement of the Department of Health, developed a two-stage strategy for handling the problem. In the first stage of the research, we conducted a descriptive national survey

of IT in the whole of England and Wales. This survey, the fieldwork for which was carried out in 1984/5, covered both the *IT policies* of SSDs, probation services and — where appropriate — voluntary agencies; and an account of *IT practice*, based on research schedules giving details of the aims, target population, activities and clients of some 1,200 IT projects across the country. All this has provided a comprehensive account of an important area of social policy. It has also provided the background for the second stage of our work, in which our approach has deliberately been different in three important ways:

- We have focused on a *narrower target group* than in the survey, concentrating only on offenders receiving IT in conjunction with a Supervision Order, and with a special emphasis (because of the IT projects which we studied) on 'heavy end' offenders.
- We have adopted a *much more detailed approach*, not only in examining the criminal and social careers of individual offenders, but also in examining the IT provision they receive, and the administrative context in which it is set.
- We have shifted our focus from a primarily descriptive to a *primarily evaluative approach*, with a particular emphasis on the question of whether IT seems to reduce criminality more than does either a custodial institution or a Supervision Order without an IT component. In addition, we have examined whether different kinds of IT seem to have a differential effect on criminality.

The second stage of the research is therefore designed to answer questions about the effectiveness of what, by the late 1980s, had become the most important form of IT in most local areas.

Long-running social research projects on policy-oriented topics can carry quite a high risk potential — the questions the research was designed to answer can sometimes seem largely irrelevant in a different policy context a few years later. But the Cambridge Intermediate Treatment research has been very fortunate in this respect because, although the IT and juvenile justice scene has changed substantially since 1984, both stages of the research have clear relevance for contemporary policy. To illustrate this, the findings of the main report on the first part of the research¹ include the following:

- a considerable variety in the IT policies being pursued by SSDs in the mid-1980s with, in particular, strong disagreements about whether 'preventive work' (however defined) should form part of the IT remit;
- substantial difficulties in SSD–probation relationships in a minority of areas;
- fairly widespread adoption of the practice of 'client mixing' (i.e. grouping together voluntary attenders and those subject to compulsory IT requirements within the same IT project);
- substantial differences, in a number of respects, between the male and female client populations for IT, and in the programmes offered by 'girls only' IT projects, as compared with others;
- important variations in the organizational structuring of IT activities within different SSDs, with evidence of distinctively different administrative problems arising from different organizational structures.

In the policy chapter of the report, some of the conclusions reached by the researchers are:

- that preventive social work with potential offenders can be justified, but such work needs to be targeted more precisely than hitherto, especially on those whose behaviour, while not criminal, is already causing concern^{2,3};
- that some IT work – for example, with certain groups of girls – may be justified as enhancing the quality of life for particular client groups, but managers should be clear that such work is 'promotional' and not strictly 'preventive';
- that the concept 'intermediate treatment' is so imprecise that its use should be discontinued;
- that there should be a clear distinction between those who are attending projects compulsorily, as a requirement of a Supervision Order, and those who are not;
- that 'client mixing' as between these two groups of clients should be discontinued;
- that provision for 'compulsory' offender-clients might be renamed 'specified activities', while provision for 'voluntary' clients might be renamed 'Voluntary Special Provision for Youth' (VOLSPY), a term which would avoid the ambiguities of 'IT', but would still distinguish this kind of work from universal youth work and education provision;
- that the organizational difficulties and tensions between SSDs and probation would justify a gradual move towards SSDs taking over the entire responsibility for social work services with juvenile offenders;
- that policy and practice variations between areas could be reduced if the Department of Health were to give a stronger national policy lead.

The Children Act 1989, when it is implemented in 1991, will transfer the 'care' side of existing juvenile court work to the domestic jurisdiction of the Magistrates' Court, creating, in effect, a clear separation between the processing of juvenile 'crime' and 'care' cases. It will also emphasize, on the care side, a sharp

distinction between *voluntary* and *compulsory* care, and place upon local authorities a duty to develop preventive work, including measures 'to encourage children within their area not to commit criminal offences' (s.7 (b)). The policy proposals offered by the Cambridge research team would usefully complement the new policy framework provided by the Act. The concept of intermediate treatment is essentially a product of the Children and Young Persons Act 1969, and has tended to incorporate the assumptions underpinning that legislation – for example, the desirability of client mixing. The cumulative effect of developments since 1969 suggests that the administrative framework of IT should now be comprehensively rethought.

None of this tackles the issue of the effectiveness of IT – a task reserved for the second stage of the research. In this stage, we have restricted our work to four local authority areas – one large city, two smaller metropolitan districts, and one shire county – and, within each, we have established three research populations: male offenders receiving Supervision Orders with IT, male offenders sentenced to custody, and male offenders receiving supervision without IT (females were excluded because of the very small numbers involved).

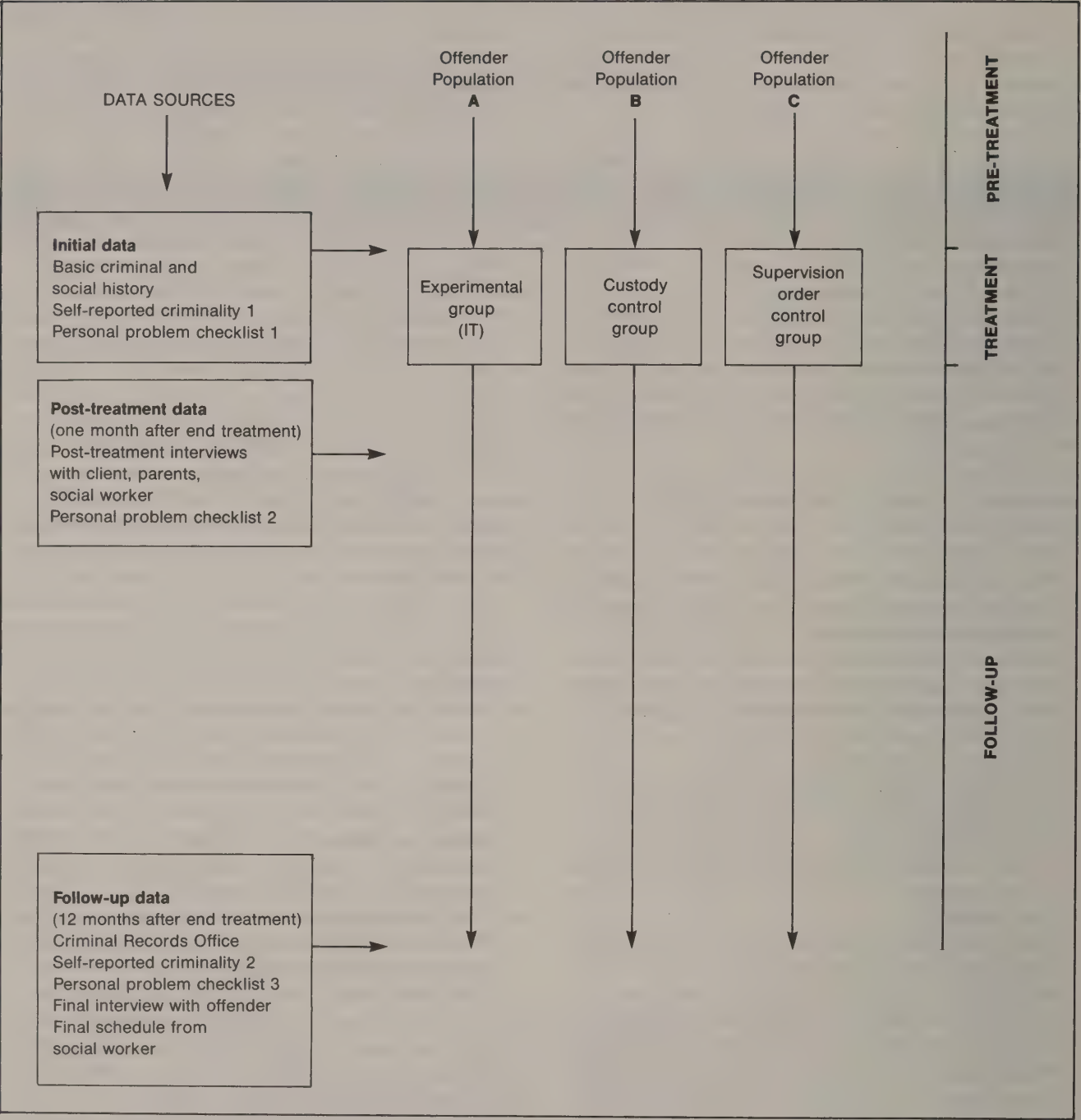
The basic research strategy for this study of effectiveness is shown in figure 3.2 overleaf. For each of the three research populations, data were collected at three points in time:

- at the beginning of treatment (so that reliable 'baseline' information was available to the research);
- soon after the completion of treatment (so that views about the content and value of the treatment could be collected from various relevant people, including the client, his parent(s) and his supervisor);
- one year after the end of the treatment (so that relevant changes in social situation, lifestyle, and criminality could be mapped).

The main aim of this part of the research is first of all to establish clearly whether IT, or particular kinds of IT, are more effective than the two control treatments in reducing criminality; and then, if possible, to explain the evaluative results obtained. The project is, so far as we know, the first in this country to employ a measure of *self-reported criminality* in a treatment evaluation study, in an attempt to overcome potential difficulties due to low (and perhaps differential) detection rates. We have been pleased that the use of this kind of instrument has caused few difficulties in the fieldwork.

The results of this evaluative study will soon be available, and will be fed into a policy context which could hardly be more appropriately designed to receive them. In 1988, the Government published a Green Paper which, among other things, praised the achievement of those who had helped to reduce the juvenile custodial population substantially during the 1980s⁴, not least by the development of 'alternative to custody' IT schemes. Through 'action plans'

Figure 3.2: Intermediate Treatment Evaluation Project:
Outline of Stage II



developed in the wake of the Green Paper, most local areas are now developing similar strategies in relation to young adult offenders, and the Government's recent White Paper⁵ emphasizes its view that credible non-custodial measures need to be more widely developed for many categories of offenders. An evaluation of the success of 'alternative to custody' IT schemes in reducing re-offending, together with an assessment of why this result has (or has not) occurred, is of obvious relevance to policy in this area.

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⁴ Home Office, *Punishment, Custody and the Community*, Cm. 424, London, HMSO (1988) paragraph 2.21
⁵ Home Office, *Crime, Justice and Protecting the Public*, Cm. 965, London, HMSO (1990)

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The Dissemination of Research Findings in Social Work

BACKGROUND

The successful dissemination of research findings in social work has to overcome numerous difficulties. Communication is not simply a matter of producing research findings or of having an important message. The successful dissemination of research requires the careful identification of the very different audiences which are addressed by any study, and an awareness of various strategies for putting messages across successfully.

In the early 1980s, numerous criticisms were made of the poor relationship between research, policy and practice in social work. The then DHSS, a principal commissioner of research, regretted that important research studies were largely ignored by social workers, that training failed to excite intellectual curiosity among new entrants to the social work profession and that distance yawned between professionals and researchers. On the other hand, practitioners claimed that researchers seeking to explain problems merely posed further questions, that they failed to address practice issues and produced unintelligible reports. Research workers, for their part, were baffled by whimsical use or misuse of their material by social workers, and by general professional indifference.

Within the DHSS, there were similar concerns about the role and use of research in fashioning policy. Reading academic reports is bound to be a relatively low priority for busy civil servants, and researchers can destroy any impact their work might have by late reporting, the use of jargon, and studies which combine tedious length with doubtful validity.

This was the background to the dissemination projects in child care, initiated by the DHSS, which are described below.

THE ROTHSCHILD MODEL

Most child care research is commissioned by the Department of Health, and virtually all large-scale studies of a longitudinal nature. The research contribution of local authorities, voluntary organizations and research councils is of course important, but it is bound to be less coordinated than that of central government. The Rothschild Report of 1971 established a customer-contractor basis for Departmental

research, in which the customer with a policy problem defines it in research terms and commissions work to answer key questions and suggest policy implications. A consensus between customer and research worker on the aims of the project is implied, and there are usually clear expectations about time limits of the studies, the methods employed and the nature of the final report.

Much good research has been commissioned on this principle. Nevertheless, the Rothschild model does have limitations, many of which have been documented. The relationship leads to a focus on policy variables — that is, things that a government department can do — so reducing scope for theoretical developments and slighting the needs of practitioners. The customer-contractor relationship also assumes a rational link between knowledge and policy decisions: in reality, policy-making is often confused, depends on decisions elsewhere, while the research which informs policy is frequently equivocal.

This structure for managing research suggested to practising social workers that issues for investigation came from outside, and that research was imposed on them. The lack of consultation and opportunity to influence research design meant that social workers had little ownership of the work and less commitment to its ideas, particularly if radical and uncomfortable changes were among the messages. Evaluative research, for example, often uses an ideal yardstick against which to assess performance and achievement, rather than starting from what is possible in the context. Judgements based on ideal criteria can appear unfair or misleading to those working in the field.

THE RESEARCH NEEDS OF SOCIAL WORKERS

This situation is complicated by the differing research needs of managers and front line workers. Practitioners have to relate generalities in research findings to their specific cases, while managers are interested in the wider messages. Department of Health research is not usually designed to be of direct help to practitioners: it is rarely sufficiently explanatory, or focused on their priorities. For all these reasons, there are problems of disseminating research, not only to social workers in general, but also to groups within the profession.

In the early 1980s, it was often unclear in social services departments how research was going to be used, who was to interpret general findings for local relevance or who should respond to new knowledge. No sanctions resulted from a failure to learn from research and no promotions came to those who had made the effort.

In fact, the relationship between research and appropriate developments in practice is often unclear. Research can be theoretical, can involve empirical surveys or can scrutinize particular situations. Developmental work can seek to influence the values of a profession, to set up demonstration projects or action research, or to design indicators useful to practitioners. The congruence between each type of research and different development strategies varies, and can change over time: for example, valid indicators are best determined from authoritative empirical evidence, while theoretical ideas reinforced by sound evidence most effectively influence the values of a welfare agency, and so on.

This mismatch between research, policy and practice prevailed until the early 1980s when several changes occurred. Firstly, the DHSS and Economic and Social Research Council (ESRC) commissioned a number of interrelated child care projects. Secondly, local authority social services and voluntary organizations were becoming more accountable and needed to scrutinize their work more rigorously. A lack of research knowledge and basic service information had been revealed by various child care inquiries and inspections and the Government was demanding that agencies secure better value for money. In addition, the increasingly professional and proactive role adopted by the Association of Directors of Social Services and the demands of a new kind of senior management enhanced the need for reliable research information, including regular monitoring of service use, and long-term evaluations of clients' progress. Finally, the courts, particularly through the guardian *ad litem* and the use of wardship proceedings, were providing a more informed scrutiny of social work decisions.

The DHSS, too, faced with the major review of child care law which led to the Children Act 1989, saw the wisdom of highlighting those research studies which had informed the new legislation. Indeed, the Act indicates a close relationship between research and policy — a remarkable advance, compared with the situation described above.

DISSEMINATION FOR THE 1980s

Given the changed situation in the 1980s, how did the Department of Health tackle the dissemination problem? The interrelated research projects commissioned by the Department provided a starting-point: while the focus of each project was specific, the types of cases studied overlapped, so that common issues and messages emerged*.

This approach had several advantages. The studies had some degree of replication, which gave the findings considerable authority; and the strategy exposed the findings to the critical scrutiny of the research community. The work also involved a wide variety of professionals and local authorities. The same kind of research strategy is being repeated in the Department of Health's current programme on child abuse. Here, there is greater emphasis than before on regular dialogue between researchers, which has already proved successful in helping to resolve the complex methodological and ethical issues surrounding this emotive issue.

The establishment, and continued support by the Department of Health, of designated research units has also contributed to the growth and increased authority of a body of empirical and theoretical research in child care. Some units are now recognized as centres of excellence, and as having expertise in particular areas of child care. Studies have been built on the foundations of previous work and the Department has encouraged longitudinal studies of child care issues. For example, the Dartington study of leavers from Youth Treatment Centres extends previous work on young offenders and adolescents in secure units, and provides comparative evidence as well as further development of theory and concepts. With this kind of knowledge base, research centres are well able to undertake dissemination: again at Dartington, we have instituted residential seminars at which social work managers can consider recent research.

One of the most enterprising dissemination initiatives during the past five years was the HMSO publication, *Social Work Decisions in Child-Care*², which reviews the common themes emerging from the DHSS and ESRC programme, and gives a short summary of each project. These reviews are linked to practical exercises dealing with issues such as access arrangements, entry to and exit from care. The publication was launched with a conference for directors of social services and elected members, and the book was sent directly to each local authority. Regional seminars were held, at which the findings of the research were discussed by delegates from every agency. Links between colleges and social services departments were also encouraged, in order to strengthen the relationship between training, research and practice: and, in this context, the role of the Social Services Inspectorate in advocating good practice backed by research evidence has been an increasingly significant factor in dissemination.

Apart from these exercises, voluntary agencies, such as the Family Rights Group, the British Agencies for Adoption and Fostering, the National Children's Bureau and the National Council for Voluntary and Child Care Organizations, were encouraged to develop

*For example, studies carried out by the National Children's Bureau, Exeter University and the Dartington Unit both included children entering care on Place of Safety Orders, and independently reached conclusions which subsequently informed policy.

a range of courses based on the new research. findings were also incorporated into training packages for social workers, and in commercially-produced information systems. Recent developments in the Open University courses, initiated by the Gatsby Open-Learning Project, have also been particularly important in reaching unqualified, part-time and inexperienced staff.

These dissemination efforts have all contributed to the development of an ethos in social services that is more receptive to research. For example, leading social work journals now have a research findings section; a market has been created for research monographs, such as the University of Bristol's Papers in Applied Social Studies; this year, the Dartington research seminars will attract 150 senior staff. It seems reasonable to conclude that child care research is increasingly viewed by social workers as a creative and positive tool.

FUTURE DEVELOPMENTS

Much remains to be done to improve the dissemination of research into child care. This may range from improving the quality of both initial and in-service child care training, to the development of and making accessible more audio-visual material.

We also need to reconsider the methods of delivering research findings. Books, circulars and papers published in journals are still the chief vehicles of dissemination. However, given the structure of the social work profession, these approaches may have a very limited audience. The professional associations and national colleges do not seek a role in extensive research dissemination, and the academic journals, such as the *British Journal of Social Work*, have to cover all aspects of the task; there is no intermediary agency for social work analogous to the Health Service's Education Council. New dissemination methods are urgently needed: video training packages, Open University courses and computer programmes, whether for instruction, monitoring or as an aid to decision-making, are possibilities. All have the advantage of flexibility and of being attractive to those who are busy and/or are deterred by academic journals. Increased receptivity to research messages by social workers,

administrators and those in wider child and youth services might also be achieved by short-term exchanges of staff between social services departments, training institutions and research centres in the way pioneered by East Anglia University. Similarly, there could be much closer liaison between the considerable research work undertaken by local authorities and that commissioned by the Department of Health.

CONCLUSION

It is increasingly obvious that issues concerning children and families, such as delinquency and abuse, continue to need the research involvement of several statutory agencies. We continually find that policies and decisions of one agency have a direct impact on the work of others. However, the orientation of research is dominated by the views of customers who commission studies and, as a result, the funding of cross-boundary investigation is little encouraged. There is, therefore, a danger that wider issues relevant to the Department's child care responsibilities receive less attention than their scientific relevance requires.


Finally, while central government seeks to maintain a consensus among all those responsible for services to disadvantaged families and children for obvious reasons, the dissemination of social research, which may take critical stance towards existing policy and practice, does not necessarily flourish in this kind of climate. Dispute and conflict among professionals engenders interest in research, and the consensus in child care — however praiseworthy on other grounds — could be seen as militating against the dissemination of research findings.

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Chapter 4

The Research Units



The articles in this chapter are a sample of the work of the Department's research units, designed to reveal the variety of work carried out. A number of the articles report findings: Goldacre and Seagroatt look at measuring health outcome through the use of the Oxford Record Linkage Study; and Macfarlane *et al* describe work on the National Study of Triplets and Higher Order Births. Leavey and Wilson's article is an account of research still at the pilot stage, aimed at helping FPCs to survey the views of service users. In contrast, Michael Hirst and his colleagues present

some valuable work on research methods, concerned in this case with communication with people who are deaf. Bevan and Dodds' articles are addressed more to general reviews of issues in their particular areas of work.

In future years, other research units will report on their programmes of work.

The views expressed in the following articles are those of the authors, and not necessarily those of the Department.

Blind Mobility Research Unit (Entry 5.15, page 95)
Allan G Dodds

Psychological Factors in Adjustment to Acquired Visual Handicap

In spite of the fact that mobility training has been available to visually-handicapped people in Britain for over twenty years, their levels of mobility have not improved significantly. Efforts to improve levels of mobility by means of the introduction of tactile maps or the provision of electronic mobility aids have similarly failed to benefit the majority of people, and recent changes in the training of workers for the visually-handicapped have yet to be evaluated in terms of their effectiveness. These findings may be partially explained by the fact that the majority of visually-handicapped people are beyond employment age, and that a substantial proportion of them suffer from an additional handicap or health-related problems. Nonetheless, the success of rehabilitation efforts appears to be less than acceptable, and there are good reasons for believing that deeper, psychological factors may be implicated.

Sudden and severe onset of visual handicap presents the individual with a number of problems simultaneously. In the first place, skills associated with mobility, daily living and communication, which have formerly been taken for granted, are immediately lost. The aim of rehabilitation is to restore these skills, and along with them, independence. However, registration as a visually-handicapped person also causes the individual to reappraise himself in relation to the sighted world, and this process of adjustment has not been given the consideration which it merits.

Two views of the relationship between the processes of adjustment and skill acquisition are revealed in current rehabilitation practice. The first is that the individual must come to terms with his visual loss before he is psychologically ready to learn new skills. This leads rehabilitation workers to believe that only emotional support and counselling are required in the initial stages, and that skill acquisition must await psychological acceptance of lost sight. This view is characterized by the 'loss' model, which emphasizes the need to grieve over the loss of the former, sighted self, and the gradual acceptance of the new, visually-handicapped self.

An alternative view is that if the client is not given immediate, practical help, he is likely to become helpless and dependent upon other people, and that this dependence and acceptance of the role of a passive recipient of help presents a major barrier to the acquisition of practical skills when they are introduced

at a later date. Workers who subscribe to this view see it as their task to restore lost skills at an early stage in order to prevent the individual from adopting a passive role from which it may be difficult to recover, and from becoming depressed in the face of their own perceived helplessness.

The most common emotional response to visual loss is depression, and depression has been found in individuals as long as four years after registration. Several reasons may be adduced for this. In the first place, the attitudes which an individual has held towards visually-handicapped people during his normal sighted life may determine how he views himself now that he has become visually-handicapped. Secondly, registration involves labelling the individual. In the absence of first-hand knowledge of visually-handicapped people, the individual may respond to labelling by taking on the imagined consequences of that label, based upon societal stereotypes. Thirdly, other sighted people may reinforce that stereotype by acting in ways consistent with it, so that the individual's negative expectations of himself are reinforced by the negative expectations of those around him. Fourthly, perception of one's incompetence in the early stages of adjustment is demoralizing, and self-esteem is lowered. This leads the individual to believe that not only is he unable to carry out even simple tasks which he could formerly take for granted, but that he is unlikely to be able to acquire the new skills demanded by the rehabilitation programme. This can lead him to withdraw into an inner world of self-pity, acquiescence and a reluctance to attempt new tasks because of the fear of failing at them.

Recent psychological research has shown that the ways in which a person perceives himself in relation to the demands of his environment have a profound influence on his behaviour and psychological health. In particular, the degree to which the individual believes or perceives that he has the power to change current circumstances is a good predictor of how successful a rehabilitation programme is likely to be. Factors have been identified which are good predictors of subsequent rehabilitation outcome in a wide variety of situations such as weight loss, cessation of smoking, drug withdrawal and even longevity.

The first is locus of control. This refers to the degree to which the individual believes that his own

behaviour will have an effect on future events as opposed to how much he believes that the future is determined by outside factors beyond his control. Individuals with a high internal sense of control tend to believe that their actions will result in change. Those with a high external sense of control believe that their actions are unlikely to result in change. Locus of control may be increased by giving the client responsibility for some aspect of his life, and this responsibility can be progressively generalized to other areas.

Another concept closely related to locus of control is that of self-efficacy. Self-efficacy has been defined as the individual's appraisal of whether or not he can produce behaviour appropriate to environmental demands. Individuals with a high sense of self-efficacy are likely to attempt new tasks, expecting to succeed at them. Those with a low sense of self-efficacy are likely to avoid attempting new tasks because they expect to fail at them. Self-efficacy can be raised by setting individuals attainable, short-term goals, and success at these tasks motivates them to try harder tasks.

Self-esteem has been identified as a motivating factor in a number of areas. People of high self-esteem tend to believe that they are capable of accomplishing new tasks; people of low self-esteem tend to believe that failure is a likely outcome. This means that individuals with low self-esteem will tend to avoid attempting new tasks, or that they will readily give up in the face of failure. However, the ways in which the individual construes the causes of failure can mediate the effects of failure on self-esteem. People make attributions as to whether failure is due to their own inability or effort, or whether it is due to bad luck or external forces beyond their control. Excuses are the most common strategies used by people to maintain self-esteem in the face of failure, and individuals vary in their attributional styles; some readily making excuses, others taking failure to indicate that they need to redouble their efforts.

Our initial research, using existing personality questionnaires, has shown that acceptance of visual handicap, attitudes towards visual handicap, anxiety, depression, locus of control, self-efficacy and self-esteem are all highly inter-related, with 50 per cent of the variance of the data being accounted for by one factor onto which these variables load. A second factor, accounting for a further 16 per cent of the variance, was identified. Item-total correlations have enabled us to reduce the original 140 items to 55 items,

with no loss of construct validity. We are currently examining the predictive validity of the final questionnaire, which we have tentatively called 'Psychological well-being', in a rehabilitation centre for visually-handicapped people.

In addition, we are in the process of establishing normative data on more elderly clients in our own local authority area. There are good reasons for believing that elderly, unemployed clients will differ in their views about themselves and in their aspirations for independence. Consequently, we intend to compare the psychological profiles of younger and older visually-handicapped people, with a view to establishing whether or not the aims of the rehabilitators coincide with those of the client in each group. It may well be that the objectives of rehabilitation will need to be clarified in order to make the system more cost-effective.

We believe that this work will serve a number of purposes. Firstly, it will enable professionals responsible for the initial assessment of clients to identify those individuals who show a poor profile across the various measures, and who may require a different type of help from those who show a good profile. Secondly, it will provide the rehabilitation centre with evidence of the effectiveness of the rehabilitation programme on the client's well-being in a way which has not been possible before. The next phase of the research will establish the relative contributions of the factors identified to the final outcome of rehabilitation and, more importantly, to the final levels of independence achieved once rehabilitation has taken place. The data will enable us to articulate more clearly a model of psychological adjustment which can be empirically tested, unlike existing stage descriptive models.

Finally, the model is not restricted to the field of visual handicap; it is equally applicable to areas such as mental handicap, the rehabilitation of amputees, and any area in which the individual must radically change his behaviour due to his altered status. It is hoped that professional workers and researchers in other areas will be able to capitalize on the findings of this research in order to maximize the impact of rehabilitation programmes.

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Centre for Primary Care Research (Entry 5.11, page 93)
Ralph Leavey and Alison J Wilson

Consumer Surveys for Family Practitioner Committees (FPCs)

INTRODUCTION

The Centre for Primary Care Research (CPCR) is designing a set of questionnaires for FPCs wanting to survey users' views of GP, Dentist, Pharmacist and Optician services. The aim is to develop small, self-contained questionnaires for selected topic areas which can be used alone or with others in the set. For example, there are 15 questionnaires designed to cover different aspects of GP services, from appointment systems to patient-doctor communications. Four FPCs have been involved with CPCR since the start of this project. They have contributed to the selection of topics and questionnaires have been piloted in their areas.

The questionnaires are still under development and we have carried out a number of pilot samples to aid in the design work. From these we can present interim results for a range of items – Access to the Surgery, Surgery Premises, Surgery Hours, Appointment Systems, Waiting in the Surgery, Consultation Length, Home Visits, Emergency Visits, Telephone Contact, Obtaining Medical Certificates, Repeat Prescriptions and Tests.

The pilot samples were small (between 300 and 600) and comparison with Office of Population Censuses and Surveys (OPCS) mid-year estimates suggests that men and the 16–39 age-range group were under-represented. Accordingly, the findings should be treated with some caution.

RESULTS

Access to the surgery

Most people lived fairly close to their doctors' surgeries. About a half lived within a mile and over 80 per cent within 2 miles. Most (80 per cent) could get there within 15 minutes, and a third took less than 5 minutes in getting there. Just under half walked, 1 in 10 used public transport and the rest went by car or bicycle. For those who said that it cost them something to get there, the amount ranged from 40p to £1.00 for most, and more than £1.00 for a small minority. Problems in getting to the surgery were mentioned by just under 10 per cent. These included a disabling illness, the distance, or commitments such as work and caring for other people: some people (7 per cent) were deterred from going by the problems involved.

The oldest people tended to live further away and were more likely *not* to use the nearest surgery. It took older people *longer*, they were more likely to use public transport (as were women); but the proportion of older people reporting problems was the same as other age-groups.

Premises

Two-thirds said that their doctor's premises were 'well-kept' *outside*, while just under 1 in 10 said it was 'in need of redecoration' *inside*. Only 62 per cent rated the interior as 'very clean'. Nearly a quarter of people used surgeries where there were either steps outside (and no ramp) or steps somewhere inside the building. This suggests that by no means are all surgery premises fully accessible to disabled people. Fifteen per cent said that the waiting area was 'cramped' and three-quarters said that the waiting area was 'crowded'. Nearly a quarter said that it was 'noisy' – the main source of noise was children. Only a small minority of surgeries (12 per cent) had play areas, and most users (64 per cent) said play areas *should* be provided. While most practices provided toilets for their patients, a substantial minority (17 per cent) were not accessible to wheelchair-bound patients.

Privacy

We also asked questions about privacy in the waiting area. Well over half (56 per cent) said that they could overhear conversations between patients and receptionists, and people thought that over half of these conversations *should* have been kept private. Sixty per cent felt that *they* could be overheard when talking to reception staff, and 4 in 10 of these people thought that *their* conversation should have been private. Four out of five people thought that there *should* be somewhere private to speak to the receptionist.

People were far happier with the level of privacy in the doctor's consulting room. However, about 5 per cent of those surveyed felt there was not enough privacy when talking to their doctor, because they knew they could be overheard.

Surgery hours

The vast majority (90 per cent) of people reported that surgery hours were convenient, although just over 1 in 10 said they had put off visiting the doctor on

occasions because the hours were inconvenient. Well over half still wanted some changes to hours: most often requested (17 per cent) were longer evening surgeries, followed by longer Saturday morning sessions. Most people said that current Saturday surgeries were for 'emergencies' only.

Appointment systems

About 4 out of 5 people usually made appointments: this is similar to the proportion found in a larger survey we carried out in the North West in 1988. Although most found the process of making an appointment trouble-free, sizeable minorities reported difficulty in getting through on the telephone (20 per cent) or complained that the surgery was closed at some times during the day (16 per cent); and a third were annoyed at receptionists asking why they wanted to see the doctor.

Most people (63 per cent) were given an appointment with their own doctor either the same day or the next day, but a third waited two days or more, and just over 1 in 10 waited more than three days. If they were prepared to see any doctor, the majority (85 per cent) were seen within two days. However, nearly three-quarters said they would prefer to see their own doctor. Most people wanting 'urgent' appointments were seen the same day — a third were seen within the hour, but 20 per cent were not seen until the next day or the day after. Just over half of those who used an appointment system preferred this; over a third wanted a mixed system and 10 per cent wanted a 'first-come, first-served' system.

Non-appointment systems

Nearly a quarter sometimes saw their GP without an appointment; some practices allowed both options, which accounts for the overlap. Almost half (45 per cent) of those users reported queues *outside* the surgery when they got there but few (10 per cent) had ever been turned away because it was too late to see a doctor. Two-thirds reported they could usually see their own doctor on the same day they wanted to, a higher proportion than those using appointment systems. People seeking to see the doctor 'urgently' were slightly more successful in seeing the doctor the same day than users of appointment systems.

Only a third of non-appointment system users preferred this system; a third would have preferred an appointment system and another third a 'mixed' system.

Waiting to see the doctor

Users of appointment systems waited less before seeing the doctor: 65 per cent were seen within 20 minutes (as opposed to 40 per cent of non-appointment users); 13 per cent waited more than 30 minutes (as opposed to 30 per cent of non-appointment users). In both cases a third said that the wait differed from doctor to doctor; and few (between

10 and 15 per cent) were told how long they might have to wait.

About 10 per cent said that the wait 'caused problems', and just under a third said that it 'irritated' them. More users of appointment systems (30 per cent) thought that the time they waited was 'unreasonable' (compared with 20 per cent of users of non-appointment systems).

Aspects of the consultation

Four out of 10 reported that their usual consultation was 5 minutes or less, just over 15 per cent said it was 10 minutes or more, and about a third said that the length differed each time. Most people overall (86 per cent) thought the time was 'long enough', but this was also linked to the time reported; just over 15 per cent did not think there was enough time for them to discuss things 'fully' with the doctor, and about 12 per cent thought it was not enough for the doctor to do all she or he needed to. A large majority (75 per cent) thought they should be able to book a longer consultation 'when necessary', and 80 per cent thought there should be special sessions set aside for when people needed longer consultations.

Daytime home visits

Just over 40 per cent had asked for a daytime visit from the doctor in the past year. Most people had wanted a visit themselves (particularly the elderly), but 1 in 3 had asked the doctor to visit a child. More requests (60 per cent) were made in the morning, and more visits were made in the morning. A small number (less than 10 per cent) said that the doctor did not visit, either because they were given advice on the telephone, or they were told to go to the surgery instead.

The vast majority (85 per cent) felt the doctors in their practice were willing to do home visits and that it was easy to get a visit; but about 1 in 7 thought their doctors were reluctant to visit and that it was difficult to get one. A similar proportion of people had, on occasion, considered asking for a visit but had not done so: about half had gone to the surgery instead and most of the rest had changed their minds. Again, a small number (10 per cent) said their hesitance was to do with difficulties they had had in the past.

Visits outside surgery hours

In the past year, 1 in 4 people had tried to contact their doctor when the surgery was closed (during evenings, nights or weekends). Most calls were made during weekday nights and were made for respondents themselves or their children. Under half (45 per cent) had spoken to someone straightaway; the remainder were told to telephone another number, or were transferred to an emergency service. Only a third said that they eventually spoke to someone they knew to be a doctor.

About three-quarters were told that a doctor would visit, but a few (5 per cent) said that they were promised a visit only after they had insisted on this.

The rest were given advice over the telephone (15 per cent) or were told to come to the surgery (5 per cent). Half of those visited said that the doctor came within an hour, but a few (8 per cent) said they waited over 2 hours. Nine out of ten said that while they waited, they were worried about the problem.

About half said the visit was made by their own doctor or another from their practice. Slightly fewer were seen by a doctor from the emergency services and the remainder by doctors from other – nearby – practices. Of those not seen by their own doctor, a large proportion (40 per cent) said this had bothered them. The vast majority said that, regardless of who saw them, the doctor had been ‘understanding’, but a few were made to feel that the visit had not been necessary.

A large number of people (1 in 3) had no idea what arrangements their practice had for emergency calls.

Phoning the doctor

Just over 20 per cent of all respondents had asked at some time to discuss a problem with the doctor on the telephone. About half of those who had telephoned had felt that the problem was an ‘emergency’. Two out of three said that they had been able to talk to a doctor – some had had to insist – but a third had been unable to, and most of these (60 per cent) had been told to come to the surgery instead. Everyone was asked if there were any ‘rules’ about when they could telephone or discuss things with a doctor. Most (75 per cent) had no idea about this. The rest claimed to know what rules there were: 1 in 10 said they could telephone at any time.

People were also asked whether their doctor had any special times set aside specifically for telephone consultations. Most did not know, and less than 5 per cent said that there were such times. The vast majority (80 per cent) thought that telephone consultations could be useful and would make use of such an arrangement: most (70 per cent) said that they would prefer such a session in the morning.

Medical certificates

Just under a fifth of those surveyed said that they had had a medical certificate (sick note) from their doctor within the past year. People were asked to think of certificates saying that they were either unfit or fit for work: for their most recent certificates, three-quarters had seen the doctor. Of those who had not seen the doctor, about half said that they ‘never’ did and the rest said that they saw the doctor only when told to make an appointment. No respondent said that the doctor was ‘too willing’ to give medical certificates, and most said that the doctor was ‘reasonable’ about this; just under 5 per cent said that the doctor was ‘too unwilling’ about giving medical certificates.

Repeat prescriptions

In the past year, almost 60 per cent of all respondents said that they had had a repeat prescription from their

doctor, and 60 per cent said that they had had more than six repeat prescriptions. Means of obtaining repeat prescriptions varied: a large proportion (40 per cent) asked the receptionist, about 20 per cent had repeat prescription cards which they gave in, and about 1 in 6 had a computer slip to hand in. Most people (70 per cent) received their prescription form either the same day or the next, and the vast majority (95 per cent) said that getting repeat prescriptions was ‘convenient’ for them.

However, only a minority (16 per cent) said that they usually saw their doctor when they needed a repeat prescription and almost 20 per cent had not seen the doctor for over a year. Most (70 per cent) either did not know what rules their doctor had about this, or said that there were no rules. Forty per cent said that the doctor should see patients regularly when they were giving repeat prescriptions.

Test and test results

About a third of the sample had had some kind of test (blood, urine, saliva, swab, X-ray) in the past year, taken at their doctor’s surgery. Most (85 per cent) were told how to collect the result, but 1 in 10 were not; and a quarter were either ‘quite’ or ‘very’ worried about the result. A quarter collected the result within 3 days, and most (60 per cent) within 7 days: about 1 in 7 waited over 10 days. A quarter thought the length of wait was ‘unreasonable’, and a small minority (5 per cent) said that they never found out the result.

Most respondents (55 per cent) heard the result from their doctor in person, a third heard it from the receptionists and the rest were written to by the doctor or the hospital. The vast majority (95 per cent) were satisfied at the way they heard the result, and most (90 per cent) said that they were able to ask all they wanted to about the test result.

CONCLUSION

CPCR has carried out several small pilot surveys over the past year as part of its programme to develop survey tools for FPCs. The findings highlight both positive and less satisfactory aspects of general practice. Getting to the surgery presented few people with problems; but getting into the surgery and movement within it could be a problem for disabled people in a large minority of surgeries which were not yet appropriately adapted. Premises were generally rated highly; but large numbers were critical of the lack of privacy when talking to receptionists. Surgery hours were convenient for most, but there were requests for longer evening surgeries and surgeries on Saturday mornings. Most felt consultations were long enough but again there was a sizeable demand for the opportunity to have special, longer sessions when patients felt it would be necessary.

Only a minority of respondents were using the telephone as a means of consulting the doctor, but there was a large demand for this option to be

extended. Most were satisfied with the way they were able to apply for a repeat prescription, but there was a large number of people who were getting repeated medication without seeing their doctor for long periods. More were satisfied at the way they received test results, but many were concerned at the length of wait.

Our surveys confirmed high levels of satisfaction with many aspects of general practice, but indicate

several areas in which there is considerable room for improvement. A major strength of the approach taken by CPR is in the breadth of coverage and the depth to which various aspects can be probed.

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National Perinatal Epidemiology Unit (Entry 5.17, page 96)
Alison Macfarlane, Frances Price and Beverley Botting

The National Study of Triplet and Higher Order Births

Although triplet and higher order births remain rare, their numbers increased rapidly during the 1980s, as figure 4.1 shows — from 12.2 sets per 100,000 deliveries in England and Wales in 1982 to 28.6 per 100,000 in 1989. In 1989, 183 sets of triplets, 11 sets of quadruplets and 1 set of quintuplets were born, compared with 70 sets of triplets and 6 sets of quadruplets in 1982. Since 1975, mortality among the babies has fallen¹.

The National Study of Triplet and Higher Order Births began in spring, 1987, and looked at a wide range of aspects of triplet, quadruplet, quintuplet and sextuplet births. Pilot studies to test the feasibility of the methods took place during 1986. The overall aim of

the Study was to look for ways of improving the care and services provided for families with children from triplet and higher births. This work was planned by a Steering Group which included clinicians, parents and members of the three organizations responsible for the survey work. These were the National Perinatal Epidemiology Unit, the Office of Population Censuses and Surveys and the Child Care and Development Group at the University of Cambridge.

ORGANIZATION OF THE STUDY

The Study was made up of a series of linked surveys. The survey methods were piloted on 1979 births, and

Figure 4.1: Triplet and Higher order Births, England and Wales, 1939-1989



Source: OPCS Birth statistics, Series FM1

births in 1980 and from 1982 to 1985 were covered in the main survey. Questionnaires were sent to consultant obstetricians about each triplet and higher order birth and about matched sets of singleton and twin births, as control groups. For multiple births there was a questionnaire about the mother and a questionnaire about each baby. Obstetricians were asked to pass the baby questionnaires to the paediatrician who was responsible for the child immediately after birth.

Questions were asked about investigations and procedures for infertility, diagnosis of multiple pregnancy, the method of delivery, the outcome for the babies and care given to mothers and babies after the birth. For mothers of singleton babies, questions were asked only about infertility. Comparative data on other subjects were derived from the Maternity Hospital In-Patient Enquiry (HIPE). When replies received from obstetricians showed that three or more children from a multiple birth had been discharged from hospital alive, questionnaires were then sent to the mother's current GP. GPs were asked about the care they provided prior to, during and after the multiple pregnancy, as well as about the current health prob-

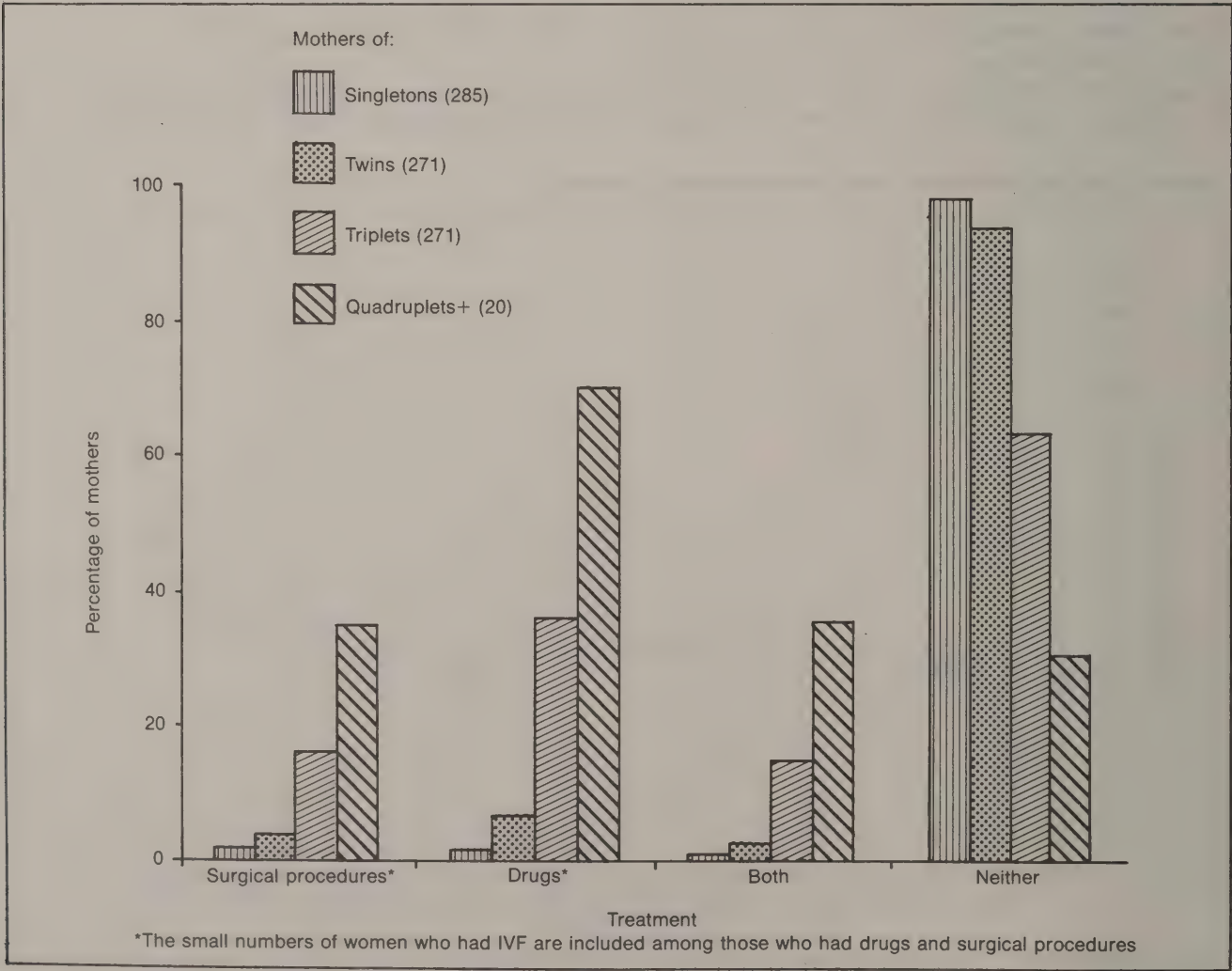
lems experienced by the children and other members of the family. Questionnaires were sent to the parents of the multiple birth, once their GPs had replied. Questionnaires were also sent to parents who contacted us directly after hearing about the Study through press publicity or other means. A fifth of those who replied were interviewed. Parents were asked about the problems they had encountered in bringing up three or more children of the same age and the availability of health and social services and other forms of help. They were also asked for their perspective of the care they received before, during and after the multiple pregnancy.

The main findings of all these surveys have been brought together in a book, *Three four and more*², published in 1990. This article summarizes some of its conclusions.

BEFORE CONCEPTION

The increase in numbers of triplet and higher order births, shown in figure 4.2, is largely a consequence of the use of drugs and procedures for infertility. In our

Figure 4.2: Treatment for Infertility in Women giving birth in 1980 or 1982-85, whose Obstetricians responded to the survey.



Source: National Survey of Triplet and Higher Order Births

survey of obstetricians, 70 per cent of mothers of quadruplets and above, and 36 per cent of mothers of triplets and above, had been prescribed drugs to induce ripening and release of eggs from their ovaries. In contrast, only 6 per cent of mothers of twins and 2 per cent of mothers of singleton babies had been prescribed these.

In Vitro Fertilization (IVF) was rarely used in our survey period, except in 1985. In IVF, popularly known as the 'test-tube baby' technique, eggs are removed from a woman's ovaries and mixed with sperm in a laboratory. If fertilization occurs, the resulting pre-embryo is transferred to the woman's womb. Statistics produced by the Voluntary Licensing Authority show a clear association between the rise in multiple births from 1985 onward and the rising use of IVF and other methods of assisted conception, mainly Gamete Intra-Fallopian Transfer (GIFT). Here, eggs and sperm are mixed together and placed in the fallopian tubes next to the womb, to allow fertilization to take place there. Research commissioned by the Medical Research Council has shown that multiple births often result from these procedures³.

Comments from parents gave rise to concern about the quality of information they received about the risks of multiple births associated with infertility drugs. There are few data about the extent to which these drugs are used, probably as a result of the patchiness of the services and the way they are concentrated in the private sector. Since most women transfer to NHS care once they are pregnant, different staff usually have to deal with the consequences for the NHS of caring for a woman with a multiple pregnancy, and the babies from the multiple birth. Problems may also arise from the fact that NHS staff may not have access to detailed records of the infertility treatment given in the private sector.

PREGNANCY

Problems were sometimes encountered with making the diagnosis of multiple pregnancy. In the majority of cases the multiple pregnancy was detected by ultrasound scan and the diagnosis was made before the twentieth week of pregnancy. Diagnosing the correct number of babies was more of a problem, however. For 6 per cent of sets of triplets and 16 per cent of sets of quadruplets and above, the correct number was not diagnosed until delivery, and many more were not correctly diagnosed until late in pregnancy. Problems arose in telling parents of the diagnosis of multiple pregnancy and these could be aggravated by professional restrictions and by lack of communication skills. Parents also felt that they needed more help during the pregnancy to start planning how to cope with their babies after the birth.

A third of mothers of twins and triplets and half the mothers of quadruplets and above had complications in the antenatal period. All mothers of quadruplets and 95 per cent of mothers of triplets were

admitted to hospital at least once during their pregnancy, either for a specific complication or for 'bed rest'.

Women varied in their views about routine admission for 'bed rest': some were relieved to be in hospital while others found this very stressful. There is no scientific evidence that this policy of routine admission is effective for women with triplet and higher order pregnancies. It involves considerable cost for the NHS, and often for the parents as well. A randomized trial is therefore needed to compare it with possible alternatives, including support to enable women to rest at home; any such trial must include a survey of the views of the women who take part.

DELIVERY

Almost half the quadruplet or higher order births covered by the obstetric survey occurred before 32 weeks of pregnancy, in other words, at least 8 weeks early, compared with a quarter of triplets and less than a tenth of twins. In contrast, only 1 per cent of singleton babies sampled in the Maternity HIPE during our study years was born before 32 weeks of gestation.

While 9.8 per cent of singleton births in the HIPE were by caesarean section, our survey showed that 28 per cent of twins, 65 per cent of triplets and 74 per cent of quadruplets and above were caesarean births. Although some of the vaginal deliveries were normal, some involved the use of forceps. The relative advantages and disadvantages of caesarean and vaginal deliveries for higher order births in different circumstances have yet to be systematically assessed by appropriate research. Given these uncertainties, it is perhaps not surprising that many parents considered that they had not been involved in discussions and choices about the method of delivery and anaesthesia. Many reported, more generally, that they did not receive the information and reassurance they needed before the delivery. Where parents had been given this, they welcomed and appreciated it.

AFTER THE BIRTH

About a quarter of mothers of triplets and a quarter of mothers of quadruplets experienced problems such as high blood pressure, blood loss, anaemia or wound infection after the birth. This put them at a disadvantage in starting to care for three or more babies. Fortunately, only very few mothers experienced severe problems.

Over half of the quadruplets and just over a quarter of triplets weighed under 1,500 grams (3.25 lbs) at birth. Although some died shortly after birth, many experienced problems which led to long periods in intensive care. Twenty-eight per cent of all live-born triplets and 62 per cent of live-born quadruplets stayed in intensive care for a month or more.

Some mothers who did not have specific complications nevertheless found it took time to recover after

the birth, and this sometimes meant that if their babies were in special care, a period would elapse before they saw them. In many cases the hospital provided a photograph and this was widely appreciated. Further problems could arise later, particularly if the mother was discharged before the babies or if the babies were transferred to a distant neonatal unit.

Many parents reported that the postnatal period was a stressful time, with uncertainties about how they would care for their babies once they were discharged. About two-thirds of parents reported that no positive plans had been made in advance to ensure that they had help and support when the babies went home. A clear need for better liaison between hospital and primary care and social services was identified. This would involve hospital social workers or liaison health visitors and the mother's own health visitor and general practitioner.

HELP FOR PARENTS AFTER THE BABIES WENT HOME

Parents needed additional help to care for their three or more babies. Initially, they needed to get some sleep and to ensure that their children were fed with the minimum of stress. Later on, they needed some time to themselves: mothers, in particular, needed some respite from continuously caring for their children. Few parents had relatives or neighbours on whom they could rely for sustained long-term help and support on a daily basis. As a result, help was needed from health and social services, but the extent to which this was forthcoming varied widely.

Help at night was seldom provided for triplets and was provided for less than half the households with quadruplets or quintuplets. On the other hand all but one household with quadruplets, and over half of those with triplets, received at least some assistance from a local authority home help — in most cases, for at least six months. General practitioners also varied in the help they gave. Some failed to appreciate the parents' problems, while others made early contact after the babies were discharged, gave regular reassurances about the children's health and made house calls for vaccinations as well as illness. Where this extra care was given the parents welcomed and appreciated it.

Some help was obtained from nursery nursing students and voluntary organizations but these seldom could provide more than supplementary or complementary assistance. Membership of a twins club or of the Twins and Multiple Births Association Supertwins Group provided sympathy, support and advice from other similarly placed parents and the chance to buy second hand clothing and equipment, but was not a substitute for regular help and support from a paid professional worker. There is, therefore, a need for a named person such as a health visitor to take responsibility for acting as an initial contact point for and to coordinate the various services and help

provided. Mothers with several young children are not in the position to take on this coordinating role themselves.

HEALTH AND DISABILITY IN CHILDHOOD

Although information from replies by general practitioners had to be interpreted with care because of the poor response rate, they showed a raised prevalence of cerebral palsy, squint, congenital malformations, pyloric stenosis and hospital admissions among children from triplet and higher order births. As the survey was confined to cases where three or more children left hospital alive, it may well underestimate the overall proportion of children with problems, as there is reason to believe that these may be more common among surviving children in sets where some babies died.

Despite reservations about completeness of information, the findings give cause for concern. A prospective study is needed to follow up triplets into childhood, and it would now be possible to undertake this through the British Paediatric Surveillance Unit.

THE PRE-SCHOOL YEARS

Most of the births included in the parents' study had been featured in the local or national press, but despite the common belief to the contrary, this did not result in free gifts for parents of triplets. The households of quadruplets and quintuplets received substantial donations from commercial companies or smaller gifts of milk, nappies or tokens. In contrast, about a quarter of households with triplets received one or more gifts of milk or nappies.

About half of the parents reported that they had moved house since the multiple birth or intended to do so shortly. A few had moved during the pregnancy after the multiple birth was diagnosed. Over half the parents of quadruplets and just over a quarter of parents of triplets had had their homes extended. Many parents reported problems in getting out of the house, with or without their children, and in transporting them. Specially designed pushchairs were expensive and too wide for pavements and doorways, so most parents used two pushchairs, a single and a double one for triplets or two double pushchairs for quadruplets. The struggle to get out to shops, clinics and pre-school facilities was a continuing problem, especially for parents who could not drive, were without a car or whose car was too small for all their children.

Pre-school children benefit from contact with other children of similar ages. One way of providing this is through supervised child care at a mother and toddler group, playgroup or nursery school. Many families were unable to use playgroups or nursery schools because of the combined problems of distance, method of transport and costs, particularly transport costs.

CONCLUSION

Our survey has identified many problems which triplets and higher order births pose for their parents and for the health and social services. Although in some cases, further research is needed, we have identified many areas where remedial action can be taken now. In doing so, it must be recognized that at every stage, triplet and higher order births entail greater costs to their parents and to the health and personal social services than the equivalent number of children of different ages.

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Social Medicine and Health Services Research Unit (Entry 5.10, page 91/92)

Mr G Bevan

Costs and Finance of Teaching Hospitals

INTRODUCTION

Teaching hospitals appear to be comparatively expensive in terms of total hospital costs divided by number of patients treated. This is one reason why acute hospitals in general, and teaching hospitals in particular¹, have attracted so much attention since the mid-1970s; but comparisons with hospitals providing routine patient-care are misleading. Teaching hospitals additionally provide specialized patient-care, research, undergraduate medical teaching, postgraduate medical training. As each of these elements may be financed in a different way, questions arise over how to identify their costs.

Perrin¹ argued that it is difficult to disentangle the costs of teaching hospitals' different 'products', because they are jointly produced. Research obviously overlaps with specialist patient-care, and medical undergraduates are taught by postgraduates in training, with both involved in treating patients (who may have common or rare conditions). Perrin made four points. Firstly, given the problem of costing joint products, the costs of each could not be accurately estimated. Secondly, to account for costs of teaching hospitals, it was vital to account adequately for their main product — namely, patient-care. Thirdly, to account for patient-care, it was necessary to be able to account for differences in case-mix below the level of speciality. Finally, Diagnosis-Related Groups (DRGs) might be a way of accounting for case-mix, but these were being criticized for failing adequately to account for severity.

The research reported here investigated how to account for differences in case-mix, and the implications of the way teaching hospitals are financed in England.

RESEARCH FINDINGS

Accounting for case-mix and case severity

To account adequately for case-mix requires a definition in terms other than services delivered. This is, however, the basis of DRGs, and of the Severity of Illness Index used to explain the higher costs of cases in DRGs in teaching hospitals^{2,3} in the United States. The Index fails to distinguish between hospitals which are treating patients who are severely ill on admission from hospitals which make patients severely ill

through poor care². Defining case severity in terms of likely prognosis at the time of admission to hospital reveals a complex relationship between case severity and use of resources.

A patient who is severely ill, for example, may or may not be expensive to treat: the patient may need lengthy operations, a long period in intensive care, a long stay in a general ward with intensive rehabilitation; or the most humane course may be to allow the patient to die at home. To make meaningful comparisons between case severity and resource use it is thus essential also to measure outcomes². A pilot study of hip fractures, however, showed that three leading case-mix measures provide poor measures of severity, and, in three teaching hospitals, there was a lack of data on outcomes after discharge⁴.

Financing English teaching hospitals

It is commonly believed that Resource Allocation Working Party (RAWP) methods make inadequate allowances for cross-boundary flows — given the more complex case-mix of teaching hospitals — and the service costs of teaching medical students. A case study of one teaching hospital showed, however, that the fact that its RAWP target was 20 per cent lower than its actual expenditure was due neither to the allowance for cases from other districts, nor to the Service Increment for Teaching (SIFT). The explanation for the low level of the target was that the district residents were using services at rates higher than the national average⁵. It was also shown that the reductions required by London teaching districts in strategies of the four Thames RHAs was closely related to spending per capita on acute services by district residents¹.

Analysis of methods of financing English teaching hospitals suggested four main conclusions. Firstly, the hospital in the case study was allowed in its target only 60 per cent of RAWP speciality costs for treating residents of its own district — a much more significant difference than any arising from patients from other districts having a more complex mix than is allowed for in RAWP speciality costs⁵. Secondly, SIFT was likely to be more than adequate to cover the extra service costs of teaching medical students¹. Thirdly, London teaching districts needed to reduce their residents' use of services, but this would be difficult, given GPs' freedom to refer, and typically, London

district residents mostly use hospitals in other districts⁵. Finally, if such reductions were achieved, there might be insufficient numbers of cases to train London's medical students¹. The fourth point was further investigated in a small study in South East Thames RHA, which suggested that, provided the medical schools used all their hospitals, there would not be a problem.

CONCLUSIONS

What are the implications of these research findings for further work, in the context of the new arrangements for the NHS from April 1991?

Health authorities are required to remove costs of teaching and research from pricing decisions, and 'ring-fence' an amount related to the continuing costs of medical teaching. The difficulty of accounting for the service costs of medical teaching means that this cannot be done adequately by April 1991. Health authorities can only be expected to distribute SIFT between and within hospitals. This would provide a starting point for relating costs to cases treated, teaching and research.

The new system of finance enables London's teaching hospitals to attract cases from outside London. In this way, they may be able to sustain levels of caseloads in London adequate for teaching their medical students. But the system of finance still requires these districts to reduce their residents' use of acute services, and it is unclear how this is to be achieved.

To account adequately for case-mix entails measuring case severity, outcomes, and resource use, which can only be done for 'tracer' conditions. We are extending our pilot study of hip fractures in three teaching hospitals to collect the necessary data prospectively.

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Social Policy Research Unit (Entry 5.23, page 100)

Michael Hirst, Lesley Jones and Sally Baldwin

Communication Skills and Research

INTRODUCTION

Everyone has views of their own and a right to express them. This is no less true of people who communicate in different ways, such as people who are deaf or have a mental handicap or learning difficulty; yet such people have often been excluded from research studies in the past, or interviewed by proxy. A major obstacle has been the lack of research methods based on communication skills different from those conventionally used in survey interviews. This gap has begun to be filled in recent years as the importance of consulting consumers of services has been recognized and the movement towards self-advocacy more widely accepted. The Social Policy Research Unit's disability research programme is built on the premise that the views of people with disabilities must be heard.

This paper describes two recent and very successful approaches to researching the views and experiences of people who communicate in different ways.

INTERVIEWING PEOPLE WHO ARE DEAF

Deaf people have been left out of research because of the problem faced by the deaf person of not being able to use or follow speech, and because interviewers have not known how to communicate in any other way. There is, however, no single approach to including deaf people in research: not all deaf people have the same way of communicating. People with an acquired hearing loss in adult life use speech and regard the spoken language as their first language. They tend to rely on lip-reading and writing things down. Most people who are deaf fall into this category.

There are, however, about 50,000 deaf people in the United Kingdom, roughly similar to the number of people who speak Welsh, whose first language is British Sign Language: it is the language in which they think, imagine and associate objects. Sign language users (usually deaf from early childhood) may be termed 'culturally deaf' and belong to the Deaf Community*: many see themselves as a linguistic minority

and would normally use interpreters in their dealings with hearing professionals. Using a written language in research may be a particular problem as deaf children often leave school with poor literacy skills.

Each of these two groups of deaf people requires a different interview method:

Interviewing deaf people who use sign language

To interview culturally deaf people successfully, it is important to use researchers who are themselves deaf and who use sign language. Deaf researchers are used for both cultural and linguistic reasons. Deaf culture is very different from hearing culture, which is often seen by deaf people as the dominant one; they may feel uneasy with hearing researchers, even when they use sign language. Cultural differences are reflected in the need to spend extra time with respondents before beginning the interview. This is to allow cultural exchanges about schooling and to share knowledge about the deaf community. In addition, sign language, like spoken language, has regional variations and time needs to be taken to get used to these. Starting the interview without this process of making the respondent comfortable in terms of both culture and language is perceived as very rude.

In a recent study of the telecommunication needs of people who are deaf, people who preferred to use sign language were interviewed by a deaf and a hearing researcher, both of whom could sign. There is no means of recording sign language in written form so a video recording was made of each interview.

This allowed eye contact to be maintained and the conversation to flow without interruption. After the interview, the video recording was translated into English by the two researchers and then analysed.

This approach was very effective. Respondents enjoyed the interviews and said they appreciated being interviewed in their own language. No one felt inhibited by the camera and video recorder, perhaps because videos are a routine way of transmitting information for deaf people¹.

Interviewing people with an acquired hearing loss

The other group of deaf people interviewed in the study of telecommunication needs were those who had developed a severe hearing loss in adult life. They differ from culturally deaf people in that they use spoken or written language as their means of communication, either by lip-reading or by writing things

*This term refers to deaf people who define themselves by their use of sign language and their membership of a cultural group with its own identity.

down. Interviewers do not need to be deaf or use sign language to work with this group of people. They do, however, need to learn how to communicate with people who are deaf.

Professional interviewers, most of whom had not worked with deaf people before, were employed for this part of the study. The researchers mounted training sessions on deaf awareness and communication skills. The aim was to help interviewers learn different skills and develop their confidence in using them. The training sessions included:

- wearing ear plugs to gain some idea of the experience of hearing loss;
- learning basic lip-reading skills and observing visual cues.

Special attention was given to the style of the interview by emphasizing the need to:

- face the light so the respondent could see to lip-read;
- catch the respondent's attention first before speaking and maintain eye contact;
- speak clearly and naturally and signal changes of topic;
- use simple gestures to supplement words and avoid casual asides which distract and cause confusion.

The questionnaire was also specifically designed to make it easier for lip-readers, for example by:

- using short, simple sentences with words distinguishable by their lip movements;
- putting the context of a question first, as this aids understanding, for example, '**Contacting your relatives** — how often do you 'phone them yourself?';
- having the questions printed on cards, with pre-coded answers where appropriate, to use when lip-reading is difficult.

Altogether, 169 people with an acquired hearing loss were interviewed using these methods². After the main survey, 30 respondents were re-interviewed to explore their views, feelings and individual circumstances in depth. Qualitative research involved further challenges in relation to interviewing deaf people. The two qualitative interviewers were accustomed to using their voices to encourage people to talk, to indicate understanding and interest, and to reassure respondents. They had to develop a new interviewing style: reassurance needed to come from visual signals, smiling and nodding, rather than tone of voice for example. The opening of the interview also needed to be simple and straightforward, allowing the deaf person and the interviewer time to become used to each other. As with the structured interviews, questions had to be phrased simply with the context or key words at the beginning of the sentence.

Both the quantitative survey of people with an acquired hearing loss and the follow-up qualitative interviews were very successful. Interviewers enjoyed the work: 9 out of 10 said they found the survey 'very interesting' and 7 out of 10 said it was the study they had most enjoyed working on in the past 12 months.

Respondents reportedly also enjoyed the interviews — there was a good response rate (86 per cent), and the information collected was of good quality. It seems clear, then, that it is possible to develop new ways of working with deaf people in order to include them successfully in research.

INTERVIEWING YOUNG PEOPLE WITH MENTAL HANDICAP

Different approaches were developed for a survey of young people with mental handicap. This survey formed part of a larger study of young disabled people's lifestyles, aspirations and circumstances. The sample was drawn from the national surveys of disabled children and adults carried out by the Office of Population Censuses and Surveys (OPCS) in 1985. At the time of the follow-up study in 1987, the young people were aged 13–22 years³.

From the outset, the intention was to talk to all young disabled people and in most cases OPCS field staff obtained an interview. However, where the young person was thought to have a mental handicap or learning difficulty, specialist interviewers skilled in communicating with people with mental handicap were used. They interviewed these young people using a shortened questionnaire developed with Debbie Roberts and Margaret Flynn of the Hester Adrian Research Centre at the University of Manchester.

Questionnaire development

A qualitative approach might ideally be the best means of interviewing young people with a mental handicap, but in this study a more structured interview was used for two reasons. Firstly, information comparable to that obtained in the main quantitative survey of other young people in the study was required. Secondly, it was important to record information in a systematic way because, in the event, 20 interviewers were needed to cover the large, geographically-dispersed sample: 166 young people fell within the scope of the study and they lived in all regions of England, as well as Scotland and Wales.

The interview covered four topics drawn from the main follow-up survey: the young people's social activities and friendships; the extent to which they took personal responsibility and exercised choice; their contacts with and perceptions of service providers such as social workers; and their plans or hopes concerning future employment, living accommodation, marriage and parenthood⁴. Within these four areas, questions were defined which could be addressed to young people with moderate or severe mental handicap. Drawing on the research literature, the following guidelines were observed:

- To encourage the young people to talk, and to retain their interest, a variety of question formats was used. Questions requiring only a 'yes/no' answer, for example, are often readily answered, although it is necessary to check for consistency of

responses because of the known tendency of this group to answer yes rather than no. 'Either/or' questions, in which two options are presented, are more effective for eliciting opinions and preferences, while open-ended questions, though difficult to answer, usually produce valid responses. Multiple-choice questions were used to help in rating the way people felt about various aspects of their lives.

- Line drawings were used to encourage responsiveness by attracting interest and allowing for non-verbal responses such as pointing. When used with 'either/or' questions, they also help reduce the tendency to choose the last option presented. The multiple-choice questions used were illustrated with five facial drawings, one set male and one female, to represent degree of satisfaction.
- Simple vocabulary and concepts were used throughout — questions regarding time and frequency, for example, were avoided, as these concepts often cause difficulty for people with mental handicap.
- The interview was designed to progress from the more factual questions to those which might reveal the young person's views and preferences.
- Short concentration spans indicated that the pace and length of the interview would be critical for retaining young people's interest. A schedule lasting no more than 30 minutes was found to be best.

The survey was intensively piloted. Pre-testing began with a group discussion in an assessment centre, to get some idea of young people's reactions to the topics and assess which types of questions might yield a full response. An interview schedule was then piloted in three stages among young people in two special schools and an assessment centre; after each pilot, all aspects of the interviews were evaluated and the schedule revised in the light of the experience gained.

Interviewing style

Unlike the previous study where professional interviewers required training in disability (deaf) awareness, the briefing sessions for this study focused on survey interview techniques, looking at the interview schedule in detail and outlining contacting procedures. Most of the interviewers worked alongside people with mental handicap and their families in their professional or private lives. Some were researchers in the field of mental handicap; others worked in community health and social services or in special education. They were thus already familiar with talking and listening to people with mental handicap.

The aim was to concentrate on the young person's comfort and conduct the interviews in as relaxed and informal a way as possible. To achieve this, most interviewers memorized the interview schedule or used only a prompt card. Questions could be asked in any order or returned to at any stage, allowing plenty

of time to answer. With respondents' permission, interviews were tape-recorded to retain eye contact and minimize distraction or anxiety caused by writing down responses. As far as possible interviews were conducted in private to avoid parents and others influencing the young person's responses; sign interpreters (Makaton) were to be used where appropriate.

Departing from normal practice, the interviewers would listen to the tape after each interview and record the young person's responses on the schedule, most of which had been pre-coded. Non-verbal information indicating how the young person was reacting to the interview was also noted. When rating satisfaction, for example, interviewers were asked to be especially attentive to the tone (animated, despondent) in which the response was made, and not merely the content. After the fieldwork, the researchers listened to the tapes, checked the information recorded on the interview schedules for consistency and completeness, and developed coding frames for open-ended questions.

Evaluation of the method

The response to the survey was good, although some interviews were not attempted where it was found that the young person had little or no communication skills, or were abandoned when it became clear that the young person did not understand the questions and gave inconsistent or no responses. Altogether, a response rate of 69 per cent was achieved⁵.

The interviewers felt that the survey methods and measures had on the whole proved adequate. There was consensus that the interview schedule had captured some of the complexities of the lives of young people with mental handicap, and interviewers generally felt that the interview flowed well and that tape recording had enhanced the quality of the information gathered. There was room for further development, however. Interviewers felt that, if the schedule had been more open, flexible and conversational, it would have been a more effective instrument for reaching young people's feelings. It worked best for the low to middle range of abilities and not towards extremes: young people with multiple handicaps and the more able were least well-served. There was no convincing evidence from the survey that line drawings had facilitated responsiveness or enhanced valid responses.

The young people apparently enjoyed the interviews; their parents were also positive and appreciated that someone was interested in their son's or daughter's views. Overall, the survey demonstrated that there is no reason why the views of young people with mental handicap cannot be included in research and other surveys.

CONCLUSION

These two studies show that it is quite possible to include people who communicate in different ways in research. This is particularly important in research on

health and social service provision. People with disabilities increasingly, and rightly, claim rights to make their own choices and express their own views of the services they receive. Moreover, contemporary policy developments clearly call for the views of service users to be taken into account. In the climate created by the Disabled Persons Act 1986 and the 1990 NHS and Community Care Bill, a premium is placed on the assessment of consumer preference and the accommodation of consumer choice. The development and use of research methods such as those described here will thus become increasingly important.

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Michael Hirst and Lesley Jones are Research Fellows and Sally Baldwin is Director of the Social Policy Research Unit, University of York.

Unit of Clinical Epidemiology (Entry 5.18, page 97)
M J Goldacre and V Seagroatt

Case-Fatality Rates as Measures of Outcome: Studies Using Medical Record Linkage

Few measures of the outcome of hospital care are routinely available within the NHS. One reason for this is that information about outcomes generally requires information concerning events at two or more different points in time — about the fact and circumstances of care, and about the subsequent course of the patients' illness. Information systems in health care have not generally been designed in ways which make this possible as a routine. Records of illness and hospital care are generally unlinked: routine information systems have been organized in terms of events rather than in terms of people experiencing the events¹. Nationally, for example, mortality records are collected and analysed routinely, but are not linked routinely to records of antecedent care. Abstracts of records of hospital in-patient care are collected routinely but are not routinely linked together for the same person.

In the Oxford region, linkable abstracts of records of in-patient care and death certificates have been collected for a number of years. This paper summarizes some of the studies which are currently underway in the Unit of Clinical Epidemiology (UCE), and which attempt to investigate case-fatality rates using these data.

The Oxford Record Linkage Study (ORLS) is a collection of computerized abstracts of death certificates and of hospital records, similar to those collected elsewhere as Hospital Activity Analysis or the Hospital Episode System, covering a defined population. The records are organized so that data about successive events, relating to the same individual, can be linked together. The initial population covered by data collection for the ORLS was about 350,000 people, and data have been collected in this population since 1963. The area covered by the study has increased in size over the years and, since 1975, data collection has covered six districts (population 1.9 million people).

For much of its history, records in the ORLS have been linked on a single-topic basis as required for particular studies. In recent years, the whole data set has been matched and linked in such a way that all records relating to every person on the file have been time-sequenced into a cumulative record relating to the individual. This is now greatly enhancing our ability to undertake studies, along the lines described below, with the potential to study conditions across a wide clinical spectrum.

CASE-FATALITY RATES AS MEASURES OF PROGNOSIS

Without record linkage, the only measure of outcome which is available from routine hospital statistics is the hospital fatality ratio. This can be calculated using the number of episodes of hospital care for a condition as the denominator; and the number of such episodes which end in death in hospital as the numerator. This measure has two obvious limitations. Firstly, if a person is admitted several times to hospital, he/she is counted several times in the denominator. Secondly, by definition, deaths which occur following discharge from the hospital in-patient episode cannot be counted in the statistics.

Record linkage makes it possible to count each person with the disease of interest *once and once only* (regardless of their number of admissions); and it provides the opportunity to identify deaths in patients *wherever the deaths occur*. One object of our analyses of case-fatality rates as measures of prognosis is to provide quantitative estimates of outcome, as measured by death, at defined intervals after admission, for a wide range of clinical conditions and surgical operations. Table 4.1 provides some comparisons between deaths in hospital and deaths within 365 days of admission to hospital for selected operations. A very different picture of the mortality of these patients is seen at one year compared with that soon after hospital admission.

TABLE 4.1: Case-fatality rates following admission for specified operations comparing deaths in hospital and deaths within 365 days of admission: deaths expressed as a percentage of the number of patients who underwent each operation

Operation (and OPCS code)	No. of patients	Deaths in Hospital		Deaths within 365 days	
		No.	%	No.	%
Cholecystectomy (522)	8058	73	0.9	243	3.0
Prostatectomy (630-5)	8099	83	1.0	732	9.0
Total hip replacement (810)	5661	63	1.1	234	4.1

These studies are also aimed at identifying some of the characteristics of patients which influence case-fatality rates. For example, in the case of acute

myocardial infarction, our analyses of factors influencing mortality within 28 days of hospital admission indicate that case-fatality rates are influenced by age (they are higher in the elderly than in others); that they are higher in females than males in younger age-groups, but that male and female case-fatality rates are similar in the older patients; and that case-fatality rates are not significantly associated with social class or marital status for this disease.

COMPARISONS BETWEEN HOSPITALS

One possible ‘prognostic factor’ included in our studies is that of the hospitals in which patients are treated. As an illustration, table 4.2 shows striking differences in case-fatality rates in three different hospitals in the Oxford Region within 28 days of patients’ admission for myocardial infarction. A finding of interpretable differences in case-fatality rates, comparing hospitals, would be of considerable interest.

TABLE 4.2: Case-fatality rates following admission for acute myocardial infarction in selected hospitals: numbers of patients, numbers of deaths within 28 days of admission, and age-standardized case-fatality rates within 28 days

Place of treatment	Patients	Deaths	Age-standardized Case-fatality rates (%)
Hospital I	1106	355	30.3
Hospital II	726	146	21.1
Hospital III	369	51	13.1

A number of possible explanations for differences in case-fatality rates do, however, need consideration before the differences could be attributed to care in the hospitals rather than the characteristics of the patients treated by them. Data shown in table 4.2 refer to all admissions to the three hospitals. In our example, Hospital III is, in fact, mainly concerned with the care of convalescent patients transferred to it. When we restricted the analysis to emergency admissions only, the data for Hospitals I and II remain very similar to those shown in table 4.2; but the total number of patients admitted to Hospital III as emergencies was reduced from 369 to 8. The apparently very low case-fatality rates in Hospital III are explained by the ‘dilution effect’ of convalescent patients. The striking differences between Hospitals I and II – both district general hospitals – remain. A number of other factors need consideration in interpretation of findings such as these², and part of our task is to explore the linked data in these respects as thoroughly as we can. We propose to report on both substantive findings and methodological issues in studying case-fatality rates as outcome indicators across a wide range of clinical conditions.

CAUSE-SPECIFIC MORTALITY AS THE ‘TIP OF THE DISEASE ICEBERG’

The aim of this series of studies is to identify patients who have died within selected time intervals (for example, 28 days, 365 days) of an admission to hospital and to compare the diagnosis on the hospital discharge record with the causes of death on the death certificate. The rationale for these studies is best explained with an example. Given a cohort of people who died within, say, 28 days of hospital admission for diabetes mellitus, how many have diabetes mellitus recorded as the underlying cause of death? How many have the diagnosis recorded anywhere on the death certificate?

In our study population, diabetes mellitus was specified as the underlying cause of death on the death certificate in only one-fifth of all people with diabetes and the diagnosis was not recorded on the death certificate at all in over one-third. Whilst, of course, sometimes patients may die soon after hospitalization from causes unrelated to the reason for in-patient care, in general it seems unlikely that death is wholly unrelated to the cause of admission.

Our studies indicate a high degree of concordance between hospital diagnoses and the underlying cause of death in patients who died soon after hospitalization for some conditions (for example, lung cancer) but low levels of concordance for others (for example, fractured neck of femur). We believe the findings from these studies may have considerable implications. They indicate the extent to which mortality statistics for individual conditions may or may not underestimate the numbers of people who die with such conditions. They indicate that considerable care may be needed in interpreting mortality statistics, for quite a wide range of conditions, as reflecting levels of mortality in people with the condition; and cautious interpretation may be required in comparing mortality rates between different places for such conditions. The findings indicate that, in general, measures of mortality in association with many conditions can only be estimated reliably by linking morbidity records of patients with the condition (for example, from hospital or primary care) to death records. We propose to extend these studies to determine whether the recording of causes of death after hospital admission for particular conditions has varied over time, and whether it varies between districts and according to such patient characteristics as age.

These findings raise the possibility of studying population-based mortality rates for some conditions which combine deaths in patients with, say, diabetes mellitus, where the diagnosis is recorded on the death certificate, with those where the patient has received hospital care for the diagnosis in (say) the 365 days prior to death. Whilst the precise nature of the underlying cause of death in any individual patient may sometimes be open to debate, such data would provide more accurate measures than those hitherto available about the number of people who died with each condition.

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Dr M J Goldacre is Honorary Director of the Unit of Clinical Epidemiology, and V Seagroatt is a Statistician within the Unit, which is based at the University of Oxford.

Health and Personal Social Services Research Programme: Listings of Commissioned Research

The chapter is divided into four parts. Part A lists the units funded by the Department of Health over the year, in alphabetical order of administrative base, followed by the name of the research establishment.

Part B lists programmes and individual projects. Entries are arranged within theme, in alphabetical order of administrative base, followed by the name of the research institution. In the case of health authorities, two administrative bodies may be listed.

Research Training Awards are found in Part C, and Part D gives a breakdown of funding for Special Medical Developments.

The dates shown relate to the total period of support. The figures in brackets show the amount of DH funding for 1989/90. Words and phrases highlighted in ***bold italics*** are explained in the *Guide to Terms*, on page ix.

NOTE: The technical medical spelling 'fetus' has been used in entry 5.17 at the request of the director.

A. Units

INSTITUTE FOR SOCIAL STUDIES IN MEDICAL CARE

14 South Hill Park, London NW3 2SB
(071 794 7793)

5.1. Director: Dr A Cartwright

The Institute studies the social aspects of health care in ways which have a bearing on social policy, concentrating on four areas: general practice; maternity services, including birth control and abortion; the particular needs of elderly people; and death and dying. A concern for the viewpoints of both those using and those providing services is fundamental to the Institute's approach. Most of the studies have been national — covering 8–20 areas of England and Wales, selected to give a random sample — and a number of methodological studies has been incorporated into the projects.

- *Living with AIDS* (K McCann, E Wadsworth)

Article — page 13

This study describes the experiences of, and attitudes towards, the care received by those with HIV-infection and AIDS. By interviewing patients as well as lay and professional carers, it aims to chronicle the relationship between care in the community and in hospital, to examine the appropriateness of care and establish levels of satisfaction.

Outputs: Report due in September 1991

- *Out-Patients and their Doctors* (A Cartwright, J Windsor)

The purpose of this study is two-fold. Firstly, it is concerned with the responsiveness of out-patient services to patients. This involves an assessment of patients' experiences and views of the referral process, and of the extent to which they want and seek referral to hospital. Secondly, the outcome of referral, as perceived by patients, GPs and consultants, is being investigated.

A postal screen of some 1,000 people on the electoral register, in each of ten randomly selected areas, identified 748 out-patient attenders, and 222 people who would like to have been referred to hospital, but were not. Interviews have been held with 77 per cent of these, and their GPs and consultants subsequently approached for their general views and experiences of out-patient referral. Information about individual referrals was sought only with the patients' approval.

Outputs: Report due in February 1992

- *Contraceptive Services and Recent Mothers* (A Fleissig, R Corney)

A random sample of 2,000 recent mothers in England and Wales was surveyed by post: 76 per cent responded. The results will be compared with previous studies in order to identify changes to contraceptive services, and will be discussed and related to recent changes in service provision.

Outputs: Report and papers are due in 1990

- *Life before Death in 1987* (A Cartwright, C Seale, G Farrow)

Mainly funded by the MRC, and based on a random sample of adult deaths, this study looks at life and care in the last twelve months of people's lives.

Outputs: *The Natural History of a Survey: An Account of the Methodological Issues Encountered in a Study of Life Before Death*, accepted for publication by the King's Fund; various papers forthcoming in 1990/91

February 1974–September 1993 (1989/90: £243,447)

1989 publications — page 157

INSTITUTE OF CANCER RESEARCH

Cancer Screening Evaluation Unit

15 Cotswold Road
Belmont
Sutton
Surrey SM2 5NG
(081 643 8901 FAX 081 770 7876)

5.2. Director: Professor J Chamberlain

The Unit's role is to ensure that innovations in cancer screening are evaluated before adoption as a service, and that monitoring systems provide adequate information for the management and further improvement of established cancer screening programmes.

- *UK Trial of Early Detection of Breast Cancer*

The effect of screening and of breast self-examination programmes on mortality from breast cancer will continue to be monitored until at least 1992 in this study of women, in eight districts, aged 45–64 years.

Outputs: Analyses of sensitivity, specificity and the accuracy of death certificate information are being prepared.

- *Case-Control Study of Screening for Breast Cancer*

This sub-study is designed to assess the validity of the case-control method, to assess other screening programmes which lack a monitored comparison population.

Outputs: Report is being prepared

- *Colorectal Cancer Screening*

A RCT of screening by faecal occult blood test, which started in 1984 and is funded by the MRC for seven years.

Outputs: Reports published

- *Monitoring of National Screening Programme*

Person-based computerized record systems have come into use for both the Breast and Cervical Screening Programmes, but further work is needed to develop outcome evaluation through linkage with cancer incidence and mortality data.

- *Melanoma Publicity Campaign Evaluation*

The Unit is analysing clinic attendance, skin biopsy rates and melanoma detection and mortality, following a campaign organized by the Cancer Research Campaign in eight districts of England and Scotland between 1987 and 1989.

- *Observer Variability in Diagnosis*

The Unit provides support for the External Quality Assessment (EQA) Programme of the National Breast Screening Programme, and for a group of Scottish pathologists in investigations of consistency in histopathological diagnosis.

Outputs: Report published

- *Economic Evaluation of Cancer Screening*

A review of literature on the economics of cervical cancer screening has been prepared.

Outputs: Report due in 1990

September 1978–December 1992 (1989/90: £328,051)

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NATIONAL INSTITUTE FOR SOCIAL WORK

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5–7 Tavistock Place
London WC1H 9SS
(071 387 9681 FAX 071 387 7968)

5.3. Director: Dr J Pahl

The NISW Research Unit carries out applied research in the field of social work and social services. It is primarily concerned with evaluating various aspects of the work of the personal social services, monitoring methods of intervention and service delivery, and assessing their outcomes.

- *The Purpose and Organization of Preventive Work with Families*

Article — page 48

This project has undertaken evaluative research into the effectiveness of supportive services for families with identified, serious child care problems, referring to two social services areas.

Outputs: Report to be published by HMSO in 1990

- *Family Health and Development*

In this follow-up study of children at risk, records for a sample of children have been traced and data on their contact with health and social services between 1981 (when they were placed on registers) and 1989 extracted.

Outputs: Report due in 1991

- *Respite Care*

A programme of work on respite care, examining the effectiveness of different types and mixes of breaks for the carers of confused elderly people, and developing guidelines for practice, based on the views of the carers, practitioners and elderly people themselves.

Outputs: First report due in Spring 1990

- *Hospital Discharge Schemes for People over 75*

This is an evaluative follow-up study of the services provided by hospital discharge schemes, based on interviews with elderly people, carers, home helps and home help organizers.

Outputs: Interim report due in Spring 1991

- *Monitoring Home Care Services (with SSI)*

The project uses *ad hoc* surveys of home help and home care clients in four departments, conducted as part of the London Home Care Inspections, to explore the targeting and delivery of home care services.

Outputs: Preliminary reports are available from the Unit

- *Ethnic Monitoring of Social Services (with REU and SSRG)*

This three-year collaborative project is exploring the variety and extent of ethnic monitoring of service delivery, and will identify good practice in monitoring and developing ethnically-sensitive services.

June 1970–July 1991 (1989/90: £337,478)

1989 publications — page 157

ROYAL COLLEGE OF GENERAL PRACTITIONERS

Birmingham Research Unit

54 Lordswood Road, Harborne
Birmingham B17 9DB
(021 426 1125)

5.4. Director: Dr D L Crombie
Deputy Director: Dr D M Fleming

The Birmingham Research Unit has been involved in gathering and interpreting epidemiological data from general practice for over 20 years. The Unit's chief source of data is the material accumulated in the Weekly Returns Service; it also uses the material gathered in the National Morbidity Studies. Currently, it is involved in the design and management of the Fourth General-Practice-based Morbidity Study, scheduled to start in the summer of 1991.

● *The Prediction of Influenza*

During the last three years, the Weekly Returns Service has expanded to cover a population of 450,000 persons. The Unit is currently analysing data accumulated over the last twenty years, to assist the interpretation of data in the earliest stages of epidemics. The problem centres on adequate discrimination between the regular winter epidemics of influenza-like illness and the more serious epidemics due to influenza 'A' virus.

Outputs: Report due in November 1990; preliminary paper submitted for publication in May 1990

● *Seasonal Variations in Common Infectious Disorders*

In this project, seasonal and annual variation is being examined: for example, mumps has a triennial cycle and this is very relevant to assessing the effectiveness of the mumps vaccine.

Outputs: Report due in September 1990

● *European Referral Study from Primary to Secondary Care*

This study has collected data from 1,500 GPs in twelve European countries. Each doctor supplied data about 30 consecutive referrals to specialists, together with encounter data during the recruitment period. The initial recruitment data have been analysed and a follow-up study involves the dates of consultation and surgical intervention.

Outputs: Report due in June 1991

● *The Problem of Inter-Practice Variability*

To help investigate the financial and clinical implications of variability in the way doctors make diagnoses and manage patients, the Third Morbidity Study is being examined to establish satisfactory methods for distinguishing between chance variability and variability attributable to practices, patients, etc.

Outputs: Report due in June 1991

● *Fourth General Practice Morbidity Study*

The Fourth Morbidity Study is planned to involve 280 doctors and around 400 ancillary staff in 70 practices throughout England and Wales. The Unit, together with the OPCS, is involved in the development and application of training programmes.

Outputs: A book is expected to be published in 1994

March 1972–December 1990 (1989/90: £171,989)

1989 publications — page 157

UNIVERSITY OF BIRMINGHAM

Wolfson Research Laboratories

Department of Clinical Chemistry
3rd Floor
Queen Elizabeth Medical Centre
Edgbaston
Birmingham B15 2TH
(021 472 1311)

5.5. Director: Professor J G Ratcliffe

The objectives of the Unit are to undertake research and development in clinical laboratory science and to promote innovations which can be taken up by industry. WRL focus on improving the effectiveness of clinical laboratories through studies into the delivery of laboratory services, and by developing and evaluating new technology, **reagents**, tests and associated equipment. The Unit brings together multidisciplinary expertise in an academic and hospital environment and has established both links with industry and mechanisms for the successful commercial exploitation of research. A recent project on enhanced luminescence received the *Queen's Award for Technological Achievement* jointly with Amersham International. The current research programme concentrates on two long-term themes, each of which contains several related projects.

STUDIES ON IMPROVED DELIVERY AND EFFECTIVENESS OF LABORATORY SERVICES IN THE HOSPITAL AND COMMUNITY, including:

- *Laboratory Resource Management — two complementary approaches*
 - the effect of regular feedback to clinicians of their use of laboratory tests — within and out of hours — and the resulting costs expressed per in-patient admission or out-patient visit. This enables clinicians to monitor their performance and compare it with their peers. A prospective study was conducted in a District General Hospital and, after one year, there was a significant decrease in tests, requests and revenue expenditure per out-patient visit — but not per in-patient admission — in the intervention group, as compared with a control group which did not receive feedback. Further studies with other groups of clinicians, including junior medical staff and hospitals, are in progress.
 - development of computer systems to assist clinical decision processes through decision-support — a subset of **expert systems**. Decision-support rules incorporate locally agreed clinical practice by issuing alerts, alarms, messages and listings, and help clinicians in their use of laboratory resources. Pilot projects are underway for therapeutic drug monitoring, but the principle has potentially wide application, including drug prescribing, antibiotic therapy and data interpretation. An important feature is the automatic reinforcement of quality of care profiles to reduce mis- and overuse of laboratory resources, as well as expensive and repetitive laboratory consultation.
- *Studies on Improved Communications and Decision-Support Systems in Primary Care*
 - development of simple systems using hand-held computers to improve the appropriateness of referrals in specialist areas such as hyperlipidaemia, diabetes, hypertension and infertility.
 - development and integration of decision-support into existing and intelligent GP computer systems to devolve expertise in patient management.
 - investigation of the doctor–computer relationship with respect to the effective use of clinical laboratories.
 - development of better methods for transmitting laboratory data directly to patient records in general practice, and studies on bidirectional communication — for example, remote requesting.

● *Evaluation of Desk-Top Analysers*

This project involves the laboratory evaluation of desk-top analysers, as well as field trials in general practice, to determine the factors which influence their cost-effective use.

● *Studies on External Quality Assessment (EQA)*

Serving over 500 laboratories, WRL have established EQA schemes for general clinical chemistry and thyroid hormones. Studies include pilot projects on cholesterol testing performed outside laboratories, and collaboration with European and international EQA.

STUDIES ON THE DEVELOPMENT AND EVALUATION OF NEW TECHNOLOGIES AND MARKERS OF DISEASE

This programme concentrates on translating relevant advances in biomedical science and technology into improved patient care and public safety. Projects include:

● *New Technologies*

- the development of electronic devices for testing close to the patient, based on porous material and using multiple tracks and switches, which are more effective than existing equipment. These systems are very flexible, applicable to a wide range of clinically useful tests and cheap to mass-produce.
- improved systems for immobilization of nucleic acid sequences to simplify the Polymerase Chain Reaction (PCR). Potentially, these may be extensively used for DNA/RNA detection in the clinical laboratory — for example, the detection of microbiological pathogens and predisposition to genetic disease.
- manipulation of the affinity and, ultimately, specificity of **monoclonal antibodies**, using genetic engineering techniques. The production of antibodies to defined specification will have significant implications for improving the quality of immunological tests.

● *Markers of Disease*

A central role of clinical laboratories is to provide tests which are effective for diagnosis, prognosis, and monitoring treatment. Several projects are concerned with identifying and critically evaluating candidate tests based on DNA, RNA and protein markers:

- *markers of DNA damage*: many pathological processes can damage DNA yielding products which can be detected in urine. Such tests are being evaluated in lung and cervical cancer and chronic inflammatory disease, rheumatoid arthritis and related auto-immune disorders,
- *markers of viral and microbial pathogens*: using PCR, the screening of donor blood for human cytomegalovirus and the detection of pathogens in immunocompromised patients is being investigated. Studies on clinical specimens which avoid the need for invasive sampling — buccal washes, sputum, et cetera — are progressing.
- *protein markers in hypercalcaemia associated with common cancers*: methods are being evaluated to assess a new, potent, calcium-regulating protein as a tumour marker.

● *Public Safety*

The Unit is studying the detection and pathological relevance of metal, pesticide and microbiological contamination of water or food, and markers of DNA damage caused by harmful environmental factors, including smoking and irradiation.

November 1976–October 1992 (1989/90: £673,351)

1989 publications — page 158

UNIVERSITY OF BRISTOL

Dartington Social Research Unit

The Courtyard
Dartington Hall
Totnes
Devon TQ9 6EJ
(0803 862231)

5.6. Director: Professor S Millham

Article — page 61

The Dartington Social Research Unit is concerned with disadvantaged children, adolescents and their families, scrutinizing both statutory and voluntary provision for those at risk. It has completed several studies of young delinquents, particularly those in security, as well as those cared for in the community. Recently, the Unit has completed investigations of the family links of children in care and of access disputes when they arise. DSRU focuses on the long-term outcomes — social adjustment, education, employment, and dependence on statutory agencies.

The Unit is currently examining, from both career and process perspectives, the problems families and children face when experiencing separation and return, the experience of families in situations where child abuse is suspected, and very difficult adolescents. DSRU is particularly interested in the outcomes of interventions, exploring the benefits and deficits of welfare on various aspects. Its approach features the historical antecedents of social services, and the client's perspective.

Working closely with policy-makers and professionals in both central and local government, the Unit disseminates its work widely — both nationally and internationally — in books, articles, and through seminars and conferences.

● *Care Careers of Young People in Youth Treatment Centres (YTCs)*

The characteristics of young people in YTCs, their progress after leaving, and very difficult young people in local authorities not using the Centres have been reported. Prospective scrutinies of young people's experiences while at the Centres and after leaving, and of similarly difficult cases placed in other secure institutions are in progress.

Outputs: Final reports due in 1993

● *Return Home as Experienced by Children in Care*

This study follows the Unit's previous concern with separation and seeks to clarify the concept of 'return home' as experienced by children in care, to identify vulnerable groups of returning children and to provide guidelines and predictive criteria for the use of social workers. Stage one of this project will be completed in 1991.

● *Parental Perspectives on Child Abuse Inquiries*

This research examines parents' and families' reactions to the suspicion of child abuse. It charts the ways in which agencies intervene in families where abuse is suspected, and monitors outcomes.

Outputs: Final report due in 1992

December 1971–January 1991 (1989/90: £185,774)

1989 publications — page 160

UNIVERSITY OF KENT

Personal Social Services Research Unit

Cornwallis Building
Canterbury
Kent CT2 7NF
(0227 764000 FAX 0227 459025)

5.7. Director: Professor Bleddyn Davies

The PSSRU undertakes analysis and research intended to help the policy world to use resources with greater equity and efficiency. Much of its work focuses on the relationship between resource inputs and outcomes: for instance, describing and explaining how variations in resources and services affect the quality of care and other aspects of the well-being of users and their families. This approach is described as the *production of welfare* approach. The Unit's work is divided into six programmes:

SOCIAL CARE OF THE ELDERLY● *Community Care and the Elderly*

The Unit has designed a series of community care projects, focusing on vulnerable elderly people, and is now involved in developing and evaluating them. The main focus is experiments in which responsibility, authority and accountability for performing some or all of the core tasks of case management are concentrated on case managers. Case managers hold budgets against which are charged all the resources which might be used as alternatives or which might complement one another in meeting needs; and have greater opportunity to match resources to needs. They have clear frameworks of information about the costs of services and their outcomes. The experiments encompass arrangements for the fuller development of case management policy and practice and for monitoring their implementation. The first experiment entered its field stage in Kent in 1977. The Unit has accumulated evidence from subsequent experiments applying the same principles to various target groups and in local circumstances which vary in service characteristics, need-related factors, local political cultures and service policies.

The research involves:

- project development aimed at improving practice, policies, procedures and systems;
- evaluation of the cost-effectiveness of project results after one year, compared with standard services;
- the reorganization of all policy and provision for the elderly in one authority along lines suggested by the research, and its subsequent evaluation;
- preparing guidelines on the assessment of elderly clients;
- analysing the relevance of the research to other client groups.

Outputs: Qureshi, Challis, Davies, *Helpers in Case-Managed Community Care*, PSSRU Studies, Aldershot, Gower (1989); monograph: Challis, *et al*, *The Dartington Community Care Project: Supporting Frail Elderly People at Home*, PSSRU (1989)

● *Home and Day Care Services*

Research is also being carried out into the relationship between resources, needs and outcomes in home and day care services in 12 areas of 10 authorities in England and Wales, involving:

- quantitative description (by needs and area) of how services are targeted, their costs to social services departments and the NHS, and their responsiveness to changing needs;
- quantitative description of outcomes after six months and three years for customers in various circumstances, together with estimates of the effects of varying services; analysis of policy, and of the assumptions of field staff and managers, focusing on case management, inter-agency collaboration, and organization;

- analysis of the nature and effects of innovations;
- monitoring the impact of *Griffiths* on policy and debate;
- the development of a framework for analysing decision-making about long-term care, in the context of a 'mixed economy' of welfare;
- analysis of the development of independently-supplied home care — the assumptions behind it and the market for it.

Outputs: Ferlie, Challis, Davies, *Efficiency-improving Innovations in Social Care of the Elderly*, PSSRU Studies, Aldershot, Gower (1989); monograph: Davies, Bebbington, Charnley, *et al*, *Resources, Needs and Outcomes in Community Services: An Overview*, PSSRU (1989)

● *Financing Care*

Following the allusion in the Griffiths Report to earlier PSSRU argument, the Unit is monitoring the development of insurance-related financing and mechanisms to assist those paying for their own long-term care. The research includes: financial brokerage services; the need for and pressure of the types of devices in the UK, the USA and elsewhere, developed during the 1980s; mechanisms for brokerage for finance and supply; the public policy implications perceived in these countries, including their impacts on public funds in general and publicly-financed care in particular, as well as their effects on the supply of care services; and the analysis of data to assess the likely spread of the use of such devices in this country.

THE CARE OF LONG-STAY HOSPITAL RESIDENTS DISCHARGED INTO THE COMMUNITY● *Care in the Community*

PSSRU is promoting, monitoring and evaluating the *Care in the Community* programme, which involves 28 demonstration projects. As well as evaluating costs and client outcomes, the Unit is analysing organizational change in the management and delivery of services.

Outputs: Final report submitted to DH in 1989

● *Psychiatric Re provision Services*

With funding from North East Thames RHA, this project is assessing the cost-effectiveness of psychiatric re provision services for people leaving Friern and Claybury hospitals.

● *Clients with Learning Difficulties*

In this study, financed by Rowntree, the costs and outcomes, after four years, for customers with learning difficulties in the *Care in the Community* projects are being investigated.

● *Voluntary Organizations*

This is an ESRC-funded study of the roles of voluntary organizations.

Outputs: A book about the initiative and project characteristics was published in 1988

THE COSTS OF CHILD WELFARE

This research covers resource issues and their implications for child welfare policies, including juvenile justice services.

● *Intermediate Treatment (IT)*

Undertaken in collaboration with the Institute of Criminology, University of Cambridge (5.87, page 114), this is a cost-effectiveness study of intermediate treatment. The Unit's work involves costing, analysing the relationships between costs and outcomes, and evaluating the cost-effectiveness of IT, custody and Supervision Order 'packages'.

● *Costs of Welfare*

A project involving costings of child welfare services, on as comprehensive a basis as possible, including the standardization of costs, and analysis of placement patterns.

Outputs: Various papers are available from the Unit

RESIDENTIAL NURSING HOMES

This is an investigation into variations in costs, prices, resident and facility characteristics of private, voluntary and local-authority-provided homes in 17 authorities.

Outputs: Papers and reports available from the Unit

AIDS AND SOCIAL SERVICES RESOURCES

- *Developing AIDS Policies in Local Authorities*

Article — page 23

The Unit is carrying out studies into the development of policy and its resources implications in local authorities in South London.

Outputs: Report submitted to DH in 1988; article forthcoming in *Social Services Research*

- *Monitoring and Evaluation of The 'Landmark'*

The Landmark Centre — an initiative by Lambeth AIDS Action in South London — provides community support for people with HIV infection and AIDS. This evaluation study includes an assessment of how the Centre influences services from other agencies.

Outputs: Monograph published in 1988

NEEDS, RESOURCES AND THE PROVISION OF SERVICES IN LOCAL AUTHORITY AREAS

PSSRU is exploring the relationship between needs, resources and the provision of services in research involving the following projects:

- *Spending Needs*

New methods of assessing the spending needs of local authority areas are being developed in this study.

- *Variations in Resources and Services*

This project seeks to explain variations between areas in terms of resources consumed and service patterns, focusing on territorial justice, the city and community care.

- *Analysis of Expenditure Trends*

Outputs: Various papers are available from the Unit

October 1974–September 1992 (1989/90: £696,801)

1989 publications — page 161

Lists of papers, reports and publications arising from these projects are available from the Unit.

UNIVERSITY OF LONDON

General Practice Research Unit

Institute of Psychiatry
De Crespigny Park
Denmark Hill
London SE5 8AF
(071 703 5411)

5.8. Former Acting Director: Dr G Wilkinson

The GPRU was established to undertake studies on psychiatric aspects of general practice and related primary care health services. Its rolling contract came to an end in September 1989 and the Unit has now disbanded. Work continued on projects which were due to be completed during 1989 and final reports and papers are expected during 1990. Enquiries should be made to the Unit's former acting director, Dr G Wilkinson, now based at the North Wales Hospital, Denbigh, Clwyd.

- *Studies Focusing on the Patient and/or the Disorder*

The Unit is reporting on the analyses of psychiatric records from the Second National Morbidity Survey and on studies about the relationships between psychiatric morbidity, social factors and health service use. Longitudinal studies of affective symptomatology and its relationship to illness behaviour, and studies on depression in elderly general practice patients are also being completed.

- *Psychiatric Morbidity in General Practice*

A major part of the GPRU's research were studies focusing on the presentation, identification and classification of psychiatric morbidity in general practice, sex difference in consultation patterns and the identification and management of social problems in general practice. Projects were undertaken on screening for psychiatric disorder, and computerized, interactive, psycho-social assessment procedures were developed.

- *The Primary Care Team/Treatment Methods*

Several projects focused on GPs, other members of the primary care team, or methods of treatment. Investigations were conducted into the decision-making process in GPs' management of psychiatric disorder. Other studies included liaison between GPs and psychiatrists, the role health visitors play in identifying and managing psychiatric disorder in primary care, and tranquilizer use.

October 1972–September 1989 (1989/90: £123,454)

1989 publications — page 162

UNIVERSITY OF LONDON

Thomas Coram Research Unit

Institute of Education
41 Brunswick Square
London WC1N 1AZ
(071 278 2424 FAX 071 833 8016)

5.9. Director: Professor B Tizard

The Unit undertakes policy-oriented research concerned with family health and functioning, the education and development of children and adolescents, and with services provided for children and their families.

● *Day Care and Later Development*

Article — page 55

This project is concerned with the implications of different types of early day care for children's development at age six, and also with the implications for dual-career families of having children at primary school.

Outputs: Report due in 1991

● *Playgroups Study*

This is a study of the role of playgroups in pre-school provision, and of changes in playgroups in the past ten years. Studies are also being carried out in individual playgroups, focusing on play leaders, mothers, and the playgroup environment.

Outputs: Final report due in spring 1991

● *Social Support and Pregnancy Outcome*

This is a RCT of the impact of a social support intervention in high-risk pregnancy on a range of maternal and infant health outcomes. The social circumstances, health and self-perceived needs of women with this kind of obstetric risk were studied, and a questionnaire survey of the health status of mothers and surviving children one year after birth was carried out.

Outputs: Final report submitted in 1989; various papers published

● *Social Identity in Adolescence*

Focusing on gender, social class, ethnic group and nationality, this project aims to explore the social identity of young Londoners. The methods used include an ethno-graphic study in two youth clubs in South London, interviews with young people, and semi-structured interviews with a representative sample of young people aged 15–17 and their parents.

Outputs: Final report due in late 1991

● *Adolescent Health and Parenting*

This study explores adolescent health beliefs and health behaviour, and the transfer of responsibility for health from parent to adolescent. Research methods include initial discussions in comprehensive schools, with groups of young people and teachers, a self-completion questionnaire on health behaviour with 300–400 young people aged 15–16, and an interview study of 80 adolescents and their parents.

Outputs: Final report due in 1992

February 1972–September 1991 (1989/90: £450,033)

1989 publications — page 162

UNIVERSITY OF LONDON

Social Medicine and Health Services Research Unit

United Medical Schools of Guy's and St Thomas's Hospitals
St Thomas's Hospital Medical School
London SE1 7EH
(071 928 9292)

5.10. Director: Professor W W Holland

Co-directors: Professor D C Morrell, Dr A V Swan

The Unit undertakes studies in the application of epidemiology to health services research, evaluation of technology and services, general practice, prevention, allocation of resources and child health.

The Unit's general strategy is to employ its resources and research expertise to increase knowledge in the areas of health service performance and resource allocation, prevention, general practice and monitoring.

The following projects were underway in 1989:

(*indicates project funding from DH and other research funds)

EPIDEMIOLOGY APPLIED TO HEALTH SERVICES RESEARCH

● *Asthma Studies**

Investigations into variations in the prevalence of asthma, treatment of asthmatics in general practice and sodium sensitivity in asthmatics.

Outputs: Reports due in 1990, 1991 and 1992

● *Need Indicators for RAWP**

This is an investigation of the appropriateness of the use of Standardized Mortality Ratios as indicators of morbidity.

Outputs: Report due in 1993

EVALUATION OF HEALTH SERVICES AND TECHNOLOGICAL INNOVATIONS

● *Genetic Services in the Context of DNA Probes*

Current analyses are examining how increased precision of risk estimates affects the outcome of pregnancy.

Outputs: Report due in late 1990

● *Lithotripsy Evaluation*

This is a comparison of extracorporeal shock wave lithotripsy against percutaneous nephrolithotomy in the treatment of renal calculi. A five-year follow-up of patients enrolled in the evaluation between 1985 and 1987 is due to begin in early 1990.

Outputs: Report due in November 1992

● *Diffusion of Health Care Technologies in Practice**

This project consists of a case study of extracorporeal shock wave lithotripsy in the UK. A report on the diffusion of lithotripsy technology in the UK, covering the key factors in each stage of the process, has been produced.

Outputs: Reported in July 1989

GENERAL PRACTICE

● *GP Referrals*

In these studies of hospital referrals by GPs, doctors' responses to simulated case histories were compared with real referral behaviour. The simulated histories seemed realistic to the doctors, although this was not supported by the objective measures of their validity.

Outputs: Reported during 1989

● *Patients' Access to Records*

The Unit is assessing the effect of granting patients access to their own clinical records, by examining the attitudes of a sample of patients, staff and consultants.

Outputs: Reported during 1989

● *Computerized Psychiatric Assessment in General Practice**

This is an evaluation of the use of a computerized psychiatric assessment on treatment and outcome in general practice. The ability of a computerized assessment to influence management and outcome in psychiatric morbidity will be compared with control groups.

Outputs: Report due in late 1990

● *The Uptake of Breast Cancer Screening**

A study to determine the effects of psychiatric morbidity, health beliefs and health locus of control on the uptake of breast cancer screening. The effectiveness of health education in increasing uptake is also being investigated.

Outputs: Report due in 1991

RESOURCE ALLOCATION AND HEALTH SERVICE PERFORMANCE

● *Costs, Finance and Planning of Teaching Hospitals**

Article — page 76

This wide-ranging work has already reported on the use of case-mix measures in the NHS and the limitations of DRGs; the use of various types of internal or provider markets; the difficulties with relationships between universities and the NHS; and critiques of the White Paper *Working for Patients*.

Outputs: Reported during 1989

● *Bladder Cancer**

This is an investigation of factors associated with the mortality of patients treated for bladder cancer in two health regions. The study was designed to evaluate whether differences in the pattern of health care intervention were associated with changes in the outcome, following treatment for bladder cancer.

Outputs: Report due in 1990

● *Stroke**

The Unit is investigating the use of a multi-district stroke register to study the epidemiology of stroke. Stroke registers have been established in three districts to try to ascertain whether differences in the Standard Mortality Ratio (SMR) for stroke can be explained by differences in the incidence or case fatalities.

Outputs: Report due in 1991

● *Outcome indicators in South East Thames RHA**

In this research, the long-term development of indicators such as potentially avoidable mortality, measures of the use of interventions of uncertain effectiveness, and measures of mortality following specific interventions are being studied.

● *Case Severity, Resource Use and Outcome**

This is an investigation of fractured neck of femur at three hospitals. The study focuses on the relationship between severity, management, resource use and outcome in this condition.

Outputs: Report due in 1991

● *Health Services in Developing Countries**

This study is measuring geographical equity in the use of health services in developing countries. Papers on methods of measuring the distribution of health services resources have been produced.

Outputs: Reported during 1988/89

● *Effectiveness and Efficiency in Surgical Management*

The study aims to describe current patterns of surgical management, including surgeons' preferences and their willingness to adopt new forms of management and constraints. The ways in which general guidelines for day-case surgery have been implemented are also being documented.

Outputs: Report due in late 1990

CHILD HEALTH SURVEILLANCE

● *The National Study of Health and Growth*

The addition of subscapular skinfold thickness to the measures taken was introduced successfully in 1989 — the study's eighteenth year.

Outputs: Numerous papers are available; reports are produced annually and the latest is being prepared

FUTURE PERSPECTIVES

In the field of health service performance and resource allocation, the Unit will be continuing its work on avoidable mortality from various causes. Work is also to continue both on the use of cancer registries for evaluating the treatment of various cancers and on stroke, to investigate differences in outcome related to social factors and the organization and availability of resources.

Furthering its research into asthma, the Unit is planning to examine the treatment of asthmatics in general practice, and the feasibility of introducing a low sodium diet as part of the management of asthma. Future studies include varying hospitalization rates for asthma and the rational use of acute resources in asthma care.

Given its expertise in the evaluation of new technology, the Unit will be involved in a RCT of extracorporeal shock wave lithotripsy, and hopes to extend this area of its interests to investigate the link between technology evaluation and health authorities' policies on its acquisition.

Fulfilling the need for research on the uptake of preventive services, the Unit is currently investigating the uptake of breast cancer screening and is developing projects in other fields.

Within the area of general practice, further work on the use of computerized assessment in treating psychiatric disorders is planned, as is research into medical audit. The Department of General Practice at UMDS is currently developing a general programme of studies which, following the implementation of the White Paper *Working for Patients*, will examine evolving practice in primary care.

Finally, the design of the Unit's National Study of Health and Growth will allow useful comparisons to be made among population groups which include ethnic minorities and the inhabitants of inner city areas.

January 1986–March 1994 (1989/90: £867,671)

1989 Publications — page 163

UNIVERSITY OF MANCHESTER

Centre for Primary Care Research

Department of General Practice, Rusholme Health Centre
Walmer Street, Manchester M14 5NP
(061 225 4214)

5.11. Director: Professor D Metcalfe
Associate Director: Dr D Wilkin

CPCR undertakes policy-relevant research in the primary health care field, focusing particularly on general practice. The Unit's current programme has four main themes: outcomes and consumer views of primary health care; the management of chronic illness; and the relationship between GPs and hospitals.

- *GP variability in the Management of Chronic Illness*

Using interviews with GPs and patients, an extensive review of patients' records, and postal questionnaires, this project is exploring the causes and consequences of variations in the patterns of care provided by GPs. The patients involved suffer from symptomatic ischaemic heart disease, chronic respiratory disorders and rheumatic disorders.

Outputs: Report due in August 1990

- *Consumer Surveys for FPCs*

Article — page 67

A survey design and analysis service is being developed to enable FPCs to monitor consumers' views on general medical, dental and pharmaceutical services.

Outputs: Report due in January 1991

- *Measures of Patient Outcome in General Practice*

Compilation of a practical guide to measures of need and outcome in primary care — for GPs, health service managers and academic researchers.

Outputs: The book is to be published in 1991

- *Choosing and Changing Doctors*

This is a survey of the extent to which patients change their GPs, the factors influencing them, and constraints on choice.

Outputs: Report due in July 1991

- *Use of the Telephone in General Practice*

In this research, postal surveys and interviews with GPs, practice nurses and patients are being conducted to provide data on professional-patient contact by telephone, particularly the provision of advice and care for patients.

Outputs: Report due in July 1991

- *Referrals to Consultants — Opinions and Uses of Data*

This is a consultancy project, identifying problems and possibilities in the collection and use of information relating to the relationship between hospitals and GPs.

Outputs: Report due in May 1990

- *Non-attendance at Out-Patient Clinics*

The extent of, and reasons for, non-attendance at general medical out-patient clinics for both new appointments and follow-ups are being explored in this project.

- *Population Indicators of Negative Outcomes in Primary Care*
The initial phase of this study examines the feasibility of using routinely-collected health service information as indicators of sub-optimal care at the primary health care level.

Outputs: Final report due in November 1992

January 1981–December 1992 (1989/90: £275,633)

1989 publications — page 166

UNIVERSITY OF MANCHESTER

Hester Adrian Research Centre

Manchester M13 9PL
(061 275 3340)

5.12. Director: Professor C Kiernan

The Centre's programme is concerned with the examination of factors bearing on care in the community for people with mental handicap and/or developmental disabilities.

- *Severe Behavioural Problems of People with Mental Handicap*

The project comprises four interrelated components:

- a survey, conducted in seven DHAs and corresponding LAs of the prevalence of severe problem behaviour and the characteristics of the individuals identified, their behaviour and methods of management;
- a study of regional and local policies and provision, and the problems of implementation, conducted in the seven surveyed DHAs;
- a study of parents' experiences, covering the behaviour of their offspring, their experiences of and views on services and costs incurred;
- a series of case studies of people with mental handicap and severe problem behaviour, to highlight critical needs and responses.

Outputs: Report due in 1990

- *Ageing and Elderly People with Mental Handicap*

A demographic survey, in one DHA/LA, of people aged over 50 with mental handicap. The survey covered people living in their own or parental homes, and in residential accommodation in the District and in hospitals — an outreach study traced those who were not receiving services. Information on characteristics, lifestyles and services was gathered, and the experiences of parents with an ageing or elderly son or daughter living at home were documented.

Outputs: Reported during 1989

- *Aspects of Ageing in People with Mental Handicap*

Covering the population in the demographic survey, this study has developed a physical health questionnaire, items for a clinical examination, and a psychiatric clinical interview: data collection is now underway. Analyses will incorporate data from the demographic survey, representing the most detailed characterization available of a population of older people with mental handicap. The study will help to define the impact of psychiatric and medical conditions on lifestyle and the need for service support.

Outputs: Report due in May 1991

- *Adaptation in Down's Syndrome Children and their Families*

This is the latest phase of the study of the Manchester Down's Cohort — children with Down's Syndrome and their parents — and relates individual and demographic characteristics of the children to measures of stress and coping in parents.

Outputs: Several articles written in 1989

September 1970–September 1993 (1989/90: £362,662)

1989 publications — page 167

UNIVERSITY OF MANCHESTER

Social Research Unit

Department of Epidemiology and Social Oncology
Christie Hospital and Holt Radium Institute
Kinnaird Road
Manchester M20 9QL
(061 434 7721)

5.13. Director: Professor A Smith

This programme is concerned mainly with the monitoring and evaluation of measures for all aspects of cancer control — prevention, screening, diagnosis and treatment — to assess how services work, how they are delivered and how they are regarded by both users and providers.

- *Monitoring and Evaluation of Cervical Screening*

This is a multi-study project examining the implementation and management of the Manchester call and recall scheme for cervical screening. The Unit is currently monitoring coverage of the target population, using routine statistics. A questionnaire survey of GPs and practice staff, examining their implementation of and attitudes towards the scheme, is also underway.

Outputs: Reports and papers due in September 1990

- *Attendees and Non-Attendees for Cervical Screening*

This study of attendees and non-attendees for cervical screening in the inner city uses interviews and records to examine women's progress through the screening system and their views about it.

Outputs: Report due in March 1991

- *Monitoring follow-up of Abnormal Smears*

This record-based study seeks to determine whether the appropriate follow-up action was taken for 800 women tested during 1987/88, whose smear test result was not negative.

Outputs: Report due in March 1991

- *DHA Arrangements for Cervical Screening*

In this research, a questionnaire survey of 190 DHAs was made, to determine the extent to which they have implemented DH guidelines for cervical screening. The study included an analysis of letters and leaflets used to invite women for screening.

Outputs: Reports and papers published in 1990

- *Consumer Satisfaction with Breast Cancer Screening*

A pilot study of women who attended Manchester Breast Screening Unit, to determine their reactions to screening, has led to the development of a structured questionnaire to measure consumer satisfaction. This has now been tested in Manchester, on a group of 300 women aged 65–75 invited for screening, and, in Wigan, on 575 women aged 50–64.

Outputs: Reports and papers published; more due in 1990

- *Delay in the Diagnosis and Treatment of Bladder Cancer*

This record-based study in four DHAs aims to identify the components of hospital-based delay in diagnosing and treating bladder cancer.

Outputs: Report due in March 1991

August 1971–March 1991 (1989/90: £105,089)

1989 publications — page 167

UNIVERSITY OF NEWCASTLE

Health Care Research Unit

21 Claremont Place
Newcastle upon Tyne
NE2 4AA
(091 222 7045)

5.14. Acting Director: Dr P R Philips
Acting Director of Research: Mr J Bond

Article — page 31

Evaluation of the quality of health care in relation to primary health care, the care of children, the care of elderly people and nursing care.

- *Northern Regional Study of Standards and Performance in General Practice*

Medical audit in primary care requires robust methods of data collection and clinical standard-setting. Currently in the final phase of analysis, this project began as a study of the effect of clinical standard-setting as an educational intervention. The methods developed, and the findings from the data-sets will be a major resource for medical audit. In the longer term, the results of *Standards and Performance* will make a major contribution to health outcome assessment in primary care.

Outputs: Reports due in 1990

- *Long-stay Accommodation (NHS Nursing Homes) for Elderly People*

The objectives of this project have been to provide a sound basis for judging the efficiency of the three experimental NHS nursing homes, and conventional care provided in geriatric wards; to identify variations in the process of care between different kinds of physical and social environments providing continuing care for very frail elderly people; and to clarify factors which might explain variations in the process and outcome of care provided in the facilities studied. It comprises seven evaluative studies, including a RCT, a multiple-case study, a cost study, and surveys of continuing-care facilities, nursing staff, relatives and volunteers.

Outputs: Reported during 1989; further reports due in 1991

- *Community Care for Adults with a Mental Handicap*

This study is concerned with the costs and effects of different kinds and levels of services provided in the community for people resettled from three long-stay Mental Handicap hospitals into five LA areas, and for a cohort of people remaining in hospital. Data are collected from the perspective of subjects and their carers. Using a case-study approach, it aims to identify features which influence the outcome of resettlement, and to make policy recommendations on resettlement methods, and the provision and resourcing of community care.

Outputs: Report due in 1991

- *Measurement, Characterization and Control of Ambulatory Care in Europe*

Within the exploratory phase of the EC's AIM project, this study is investigating the development of European minimum data-sets for primary and community care. It has also examined the management of resources, and the IT and T infrastructure which efficient and effective health care requires. Partners in the project, drawn from clinical and industrial fields, are based in Spain and the Netherlands.

Outputs: Report to the Commission due in 1990

● *Primary Nursing and Primary Medical Care: a Comparative Study in Community Hospitals*

This project was established to inform North Derbyshire HA of the implications of two innovations in care for elderly people. These were nursing care according to the principles of primary nursing, and GPs caring for their own elderly patients in a community hospital, directed by a consultant physician responsible for the medical care of elderly people.

Outputs: Report due in 1990

● *Predicting a Mother's Choice of Infant Feeding Method*

This study has developed a questionnaire, administered by midwives to mothers at the antenatal booking visit; its accuracy and acceptability are currently being tested. From the questionnaire, a score is allocated to each mother to indicate the likelihood that she will breast-feed. This information will be used in attempts to target education more effectively, ultimately to increase breast-feeding rates.

Outputs: Report due in Autumn 1990

● *HIV Infection, AIDS and Community Nursing Staff in Scotland*

This project, carried out late in 1988, assessed the involvement of community nursing staff in Scotland in work associated with HIV infection and AIDS, investigating their knowledge, beliefs and intentions regarding practice.

Outputs: Reported during 1989

● *The Northern Regional Community Support Centre*

This project is monitoring the activities of a multidisciplinary centre set up as part of the development of community-based services to support people with HIV-related illnesses.

Outputs: Report due in 1990

● *Sainsbury Trust Adult Community Physiotherapy Project*

This is a RCT to assess the effects of community physiotherapy as an alternative to hospital out-patient services and other *ad hoc* arrangements. The trial describes patients referred by GPs, the service provided; assesses changes in client function, health status or lifestyle, use of other services; and examines clients', carers' and GPs' perceptions of the service.

Outputs: Report due in March 1992

● *Outcome Measures for use by Primary Care Teams*

Outcome measurement for specific clinical conditions is at an early stage of development. This Delphi study has successfully established a consensus between practising doctors in both conditions and outcome measures.

Outputs: Report due in 1990

● *Factors that Influence GPs' Referral Decisions*

Analysis of the factors that influence GPs' decisions to refer patients to hospital has revealed a highly complex decision-making process, influenced by a wide range of factors. These include doctors' relationships with colleagues, patient pressure and medico-legal issues.

Outputs: Report due in 1990

● *Improving Referral to Hospital*

In this collaborative study with Sunderland Royal Infirmary, interviews are being held with patients, GPs and consultants to discover their expectations and perceptions of referral. Results will be used to improve communication and the quality of referral to hospital.

Outputs: Report due in March 1992

October 1969–March 1993 (1989/90: £496,673)

1989 publications — page 167

UNIVERSITY OF NOTTINGHAM

Blind Mobility Research Unit

Department of Psychology
University Park
Nottingham NG7 2RD
(0602 484848 x 3187)

5.15. Director: Professor C I Howarth

Deputy Director: Dr A G Dodds

The Unit undertakes research into the problems of severe visual handicap, whether of a perceptual, cognitive or psycho-social nature. It aims to identify factors which inhibit independent mobility in the visually-handicapped and devises ways of overcoming them.

● *Low Vision*

Work on computer-generated graphic displays has shown that they are better predictors of locomotor performance than are existing measures of acuity and field, and that, with encouragement and practice, clients' visual performance can be improved: this extends to their travel performance indoors. These findings suggest that psychological factors need to be investigated, together with an examination of the relative influences of central and peripheral vision on locomotor control.

● *Aspects of Training*

The use of tactile maps and electronic mobility aids among the visually-handicapped is low, and many clients appear not to benefit from training in basic mobility techniques. BMRU's research indicates that low vision clients are not well catered for by existing training techniques, and that more attention must be paid to the beliefs and attitudes of clients towards their own independence.

Outputs: Dodds A G, Cooper J, Lee M, Yates L, 'Psychological factors in rehabilitation', in *Proceedings of the International Conference on the Education of the Visually Handicapped*, Warwick University, March 1990 (in press)

● *Psycho-Social Aspects of Mobility*

Article — page 65

The concept of personal effectiveness is central to understanding the ways in which visually-handicapped people respond to being labelled. Clients who exhibit negative attitudes towards visually-handicapped people show a low acceptance of their visual handicap, have a low sense of self-esteem, display anxiety and depression, and have a low sense of personal control and efficacy. These factors are highly interdependent, and research is currently in progress to determine the causal relationships between them, with a view to improving the ways in which rehabilitation is delivered, concentrating on how clients with different psychological profiles respond to the types of help they are given.

Outputs: Howarth C I, 'The psychology of helping behaviour', in Hackman W D (ed), *The Oxford Companion to Science*, Oxford, OUP (in press)

March 1970–December 1990 (1989/90: £149,663)

1989 publications — page 169

UNIVERSITY OF OXFORD

Childhood Cancer Research Group

57 Woodstock Road, Oxford OX2 6HJ
(0865 310030)

5.16. Director: Dr G J Draper

The CCRG undertakes a programme of epidemiological studies of childhood cancer and leukaemia, together with follow-up studies of children treated for these diseases.

- *National Registry of Childhood Tumours*

Cancer registrations for children under 15 in England, Scotland and Wales, and also death certificates for deaths from neoplasms occurring before the age of 20 are sent to the CCRG. Notifications are also received from the UKCCSG and the MRC Leukaemia Trials Office. The registry forms the basis of much of the work below and is a source of information for other research workers.

- *Incidence of Childhood Tumours*

This project involves the calculation of age-sex specific incidence rates for each type of childhood cancer, and the analysis of international and ethnic variations in these rates.

Reports: Papers are being prepared

- *Aetiological Studies*

These studies include the development of methods of linking records to determine the incidence of childhood cancer among groups exposed to a possible aetiological factor.

- *Genetics of Childhood Cancer*

Studies of childhood cancer among siblings and of the risks of retinoblastoma and other cancers in relatives of children with retinoblastoma are in progress.

- *Analysis of Survival Rates*

Survival rates for each type of childhood cancer are being calculated. Trends in survival rates and the relationship of these to the centralization of treatment are being analysed.

- *Clinical Studies*

These are collaborative studies (with paediatric oncologists) on the natural history and treatment of various childhood tumours.

- *Long-Term follow-up Studies of Survivors*

Studies partly funded by the CRC and the LRF include: long-term mortality rates and the causes of 'late deaths' among children surviving for at least three years after treatment; the incidence of second primary tumours and their relationship to treatment and genetic diseases; studies of survivors' pregnancies and offspring.

Reports: Reports on all the above projects are expected during 1990/91. A review of the epidemiology of childhood cancer will appear in a book on paediatric oncology in 1990; and a collaborative report on the study of childhood leukaemia in post-Chernobyl Europe, co-ordinated by IARC, is planned for 1990.

- *Geographical Studies of Childhood Cancer in Britain*

Funded by DH and the NRPB, geographical variations in UK incidence rates are being examined.

Reports: Monograph on the UK geographical distribution of childhood leukaemia and non-Hodgkin lymphomas is planned for 1991

April 1975–August 1994 (1989/90: £297,176)

1989 publications — page 169

UNIVERSITY OF OXFORD

National Perinatal Epidemiology Unit

Radcliffe Infirmary, Oxford OX2 6HE (0865 816876)

5.17. Director: Dr I Chalmers

NPEU provides information which can promote effective use of resources in the perinatal health services.

SURVEYS AND STUDIES USING OBSERVATIONAL DATA

- *Analysis of Mortality and Other Trends and Variations*

Documenting and analysing trends and variations in maternal and infant mortality, stillbirths, termination of pregnancy, low birthweight and care resources; NW Thames maternity information project.

- *Surveys of Morbidity*

Oxford regional child development project; regional register of early childhood impairment; standardization of cerebral palsy recording and reporting, and of defining criteria for very low birthweight infants; rehospitalization patterns among very low birthweight infants.

- *Surveys of Practice*

Referrals for neonatal medical care; the midwife's role in preventing postpartum morbidity.

- *Other Studies using Observational Data*

Study of Triplet and Higher Order Births (article — page 71).

RANDOMIZED CONTROLLED TRIALS

- *Problems in Being Born too Early or Too Small*

MRC-RCOG cervical cerclage trial; social support and pregnancy outcome; MRC collaborative low-dose aspirin study in pregnancy; collaborative European trials of prophylaxis for very preterm neonates; collaborative RCT of dexamethasone in neonatal chronic lung disease; multicentre RCT comparing early and conservative management of post-haemorrhagic ventricular dilatation in neonates; study of infants at risk of or with respiratory insufficiency; Oxford controlled trial of artificial ventilation; preventing low birthweight with oral salbutamol.

- *Identifying and Managing the Compromised Fetus or Baby*

MRC European collaborative trial assessing the safety of chorion villus sampling for fetal diagnosis; multicentre trial of maternal fetal movement counting; identifying cerebral palsy among children born during the Dublin RCT of intrapartum fetal monitoring.

- *Other Trials*

Multicentre trial of treatments for inverted and non-protractile nipples; treatments for 'late' dyspareunia after vaginal delivery; comparing three fetal scalp electrodes.

- *Economic Evaluation and Randomized Trials*

Antibiotic prophylaxis and caesarian section; preventing neonatal respiratory disease syndrome; EC project on managing labour in primigravidae.

SYNTHESES OF RESULTS; EVALUATING CARE; DATABASES

- *Synthesis of the Results of Controlled Trials in Overviews*

Oxford Database of Perinatal Trials; Effective Care in Pregnancy and Childbirth (OUP).

- *Improving Validity in Syntheses of Controlled Trials Results*

Survey to identify unpublished trials; cohort study of trials published as abstracts.

- *Databases of Ongoing Research*

International Register of Unpublished Trials (IRUPT); Midwifery Research Database (MIRIAD).

January 1978–December 1991 (1989/90: £317,802)

1989 publications — page 169

UNIVERSITY OF OXFORD

Unit of Clinical Epidemiology

Old Road
 Headington
 Oxford OX3 7LF
 (0865 64861 x 380 FAX 0865 68330)

5.18. Director: Dr M J Goldacre

The Unit undertakes epidemiological and health services research, particularly by using medical information systems and medical record linkage, and by conducting related research in primary care. It also aims to develop expertise and innovations in medical information systems technology and techniques. The Unit's databases — notably the Oxford Record Linkage Study (ORLS) — can also be used as an 'information laboratory' to address specific issues raised by researchers and policy-makers outside the Unit.

- *Descriptive Epidemiology of Hospitalized Diseases*

This is a multi-study project using record linkage to provide information about the epidemiology and characteristics of a wide range of clinical conditions. Components of the studies include analysis of each condition in relation to, for example, age, gender, marital status, blood group, trends over time, seasonal patterns where applicable, and geographical variation.

- *Trends over Time in Workload in Acute Specialities*

This series of studies focuses on trends in workload within each speciality. Hospital admission rates in the acute sector have been increasing in England for many years, and these studies aim to assess how far the rise represents an increase in the numbers of individual people treated, an increase in multiple admissions per person, the changing demographic profile of the population, and/or changes over time in the treatment of individual clinical conditions within the speciality.

- *Use of Hospital In-Patient Services — the Likely Impact of Demographic Change*

The aim of this research is to estimate the profile of hospital care which would be expected, at contemporary rates of usage, as a result of the changing age-structure of the population. To achieve this, analyses of contemporary hospitalization rates in each age-group will be applied to the projected size and composition of the population in future years.

- *Emergency Readmission Rates and Case-Fatality Rates as Measures of Outcome for Hospital In-Patient Care*

Article — page 82

Record linkage is being used to study rates of readmission and death following hospital admission, for a wide range of clinical conditions. This series of studies aims to provide estimates of prognosis following hospital care; to quantify factors influencing prognosis — age, gender, social class and marital status, for example; to study trends over time in these rates; and to compare rates between different geographical locations and types of hospital. We hope that the results will provide useful information for the routine development of measures of health care outcome.

- *Trends and Inter-District Variation in the Time Patients Spend in Hospital*

In studying the duration of time spent in hospital, record linkage enables transfers and multiple admissions per person to be taken into account. The method is being used in this project to study lengths-of-stay per episode and the total time spent in hospital per person per annum.

- *Time Spent in Hospital by the Elderly in their Final Year of Life*

As one specific application of the above project, this study aims to determine whether the increase in life expectancy of the elderly in recent years has been accompanied by an increase in time spent in hospital in the last year of life. Preliminary results indicate that the gain in life expectancy has not been at the expense of any substantial increase in time spent in hospital.

- *Hospital Transfers and Readmissions across Administrative Boundaries*

As a result of the Körner recommendations, health districts are implementing hospital information systems which incorporate linkage of hospital spells within the same district. Data from the ORLS — which can be linked across districts — are being used to assess the extent to which episodes of care involving transfer or readmission are divided between districts, and therefore 'missed' by linkage within one district only.

- *Variation between General Practices in Out-Patient Referral Rates*

A collaborative study of referrals to out-patient clinics, involving 127 GPs in 33 practices has been conducted. Records were kept of 18,754 referrals which included data on diagnoses and reasons for referral. These data are being analysed to report on variation between general practices in out-patient referral rates. Studies are also being undertaken on outcomes of GPs' referrals to hospital for selected conditions.

- *Epidemiological Aspects of Self-Poisoning in Teenagers; and of Accidents in Pre-School Children*

These projects are two examples of the kind of study of conditions which can be effectively undertaken using medical record linkage. Data on admissions for self-poisoning in teenagers have been analysed to determine population-based rates of occurrence, and the main characteristics of self-poisoning; the extent to which individuals repeat self-poisoning; and how far hospital admissions for self-poisoning are predictive of an eventual fatal episode.

Records of admissions for accidents in pre-school children are being analysed in similar ways, including an assessment of the degree to which individual children experience multiple admissions for accidents.

- *Development of Techniques for Record Linkage and in the Design and Use of Medical Information Systems*

The development of techniques and expertise in medical information systems is an integral part of the Unit's work. This includes the refinement and application of methods in medical record linkage, in the analysis of time-sequenced records and, more generally, in the management and uses of very large databases.

Outputs: Results from these various studies are due in 1990 and 1991

January 1981–October 1992 (1989/90: £514,504)

1989 publications — page 172

UNIVERSITY OF SHEFFIELD

Medical Care Research Unit

Beech Hill Road
Sheffield S10 2RX
(0742 766222 x 2842)

5.19. Director: Professor B T Williams

The Unit works in the fields of health technology assessment, the evaluation of acute hospital services, and the organization and delivery of primary health care.

- *RCTs of Biliary Lithotripsy and Cholecystectomy*
Involving a second-generation Wolf lithotripter, this is a cost-effectiveness study of two treatment methods for gallstones.

Outputs: Report due in March 1991

- *Accident and Emergency (A&E) Services*
This MRC-funded study has examined the trends and determinants of demand for A&E services in England.

Outputs: Reported to the MRC in November 1989

- *Voluntary Deregistration and non-NHS Doctors*
This is a study of medical practitioners who deregister voluntarily, and a follow-up of those not working for the NHS three years ago. It aims to document manpower availability for the Advisory Committee on Medical Manpower Planning.

Outputs: Report due in May 1990

- *Domiciliary Oxygen*
This research is assessing the impact of DH guidelines on domiciliary oxygen prescribing, and the geographical distribution of use in relation to supplying company contract areas.

Outputs: Report due in July 1990

- *Three-Year Non-Attendees at General Practice*
Arising from the new GP contract, to be implemented in 1990, this project is examining a national sample of GPs' patient records to determine the proportion of non-attendees, and is studying the effects of GPs issuing invitations for health promotion advice in five areas.

Outputs: Report due in March 1991

- *Nursing Triage/Nurse Practitioners in A&E Departments*
This is a literature review, leading to a study starting in April 1990.

- *Alternative Health Care*
Funded by the Nuffield Provincial Hospitals Trust (NPHT), this project describes the distribution of non-medical practitioners of non-orthodox care in Britain, and is conducting a time-sample study of their patients' problems and use of orthodox and alternative care.

Outputs: Report to NPHT in April 1990

- *Exercise-Related Injury*
With Sports Council funding, a national, postal questionnaire survey of exercise habit, injuries sustained and source of care has been conducted to assess the occurrence of exercise-related injury and resultant demand for health services.

Outputs: Report due in 1991

December 1973–March 1995 (1989/90: £273,303)

1989 publications — page 172

UNIVERSITY OF SURREY

Nursing Practice Research Unit

Guildford GU2 5XH
(0483 571281)

5.20. Director: Professor R Crow
Deputy Director: Dr A Mulhall

NPRU pursues research with both applied and fundamental aspects which will advance the scientific basis of nursing practice. A priority theme — the demands on, and effectiveness of, acute sector services — has directed the Unit's programme to date. The research therefore provides information for improving direct patient care, optimizing the provision of services and directing nursing policy.

- *Identification of Biological and Environmental Parameters Leading to the Genesis of Pressure Sores*

Project Leader: Dr M Clark

This study will provide a more complete model of pressure sore aetiology by measuring and ranking, in a discriminant analysis, those factors which may cause or predispose patients to these wounds.

Outputs: Report due in August 1990

- *Aetiology, Incidence and Prevention of Catheter-Associated Bacteriuria*

Project Leaders: Dr A Oraedu, Dr A Mulhall

This research will determine the effects of errors in catheter and drainage-bag maintenance on the incidence of bacteriuria, using ward observations and an *in vitro* bladder and catheter model. The study will also define the aetiology and sources of infection in catheterized patients.

Outputs: Report due in November 1990

- *Costs of Pressure Sores*

Project Leader: Dr M Clark

A new methodology for costing pressure sores is being developed in this study. The balance of costs between prevention and treatment, and the relative costs of sores of different severity are also being determined.

Outputs: Report due in December 1991

- *Nursing Management of Leg Ulcers in the Community*

Project Leader: Dr N Cullum

This project is a critical analysis of both published and unpublished research relating to the management of leg ulcers in the community. It aims to identify practice which is research-based and to highlight areas where further study is needed.

Outputs: Report due in August 1991

January 1979–April 1993 (1989/90: £222,987)

1989 publications — page 173

UNIVERSITY OF WALES

Centre for Social Policy Research and Development

School of Sociology and Social Policy
Bangor LL57 2DG
(0248 351151 x 2224)

5.21. Director: Dr G Grant

The Centre undertakes theoretical and applied research in the fields of social care and social control, in ways which have a bearing on social policy. Its DH-funded research concerns social gerontology, mental handicap and mental health, linked by interests in the relationship between formal and informal care.

● *Longitudinal Study of Ageing*

In its third phase, this study provides a record of the lives of elderly people and their support networks over ten years. The survey and qualitative methods used have helped to highlight the importance of support network variations to adaptation, service use and survival in old age.

● *Development of a Support Network Typology*

Development work on putting a support network typology into practice has been completed as part of the longitudinal study above. The typology is to be field-tested by various professional groups, as a way of assessing case management practices.

● *Service Histories of Elderly People*

Using interviews with elderly people and service providers as well as examining case records, an analysis of elderly people's service histories over ten years has been completed.

● *Policy Implementation Studies — the All-Wales Mental Handicap Strategy*

These studies of new planning and service delivery systems have been principally concerned with an evaluation of strategies for consumer involvement, multidisciplinary teamwork and the capacity of local agencies to deliver needs-led services.

● *Service Packaging and Mental Handicap*

A comparative analysis of different approaches to service packaging across counties in Wales, involving persons with a mental handicap, informal supporters and professionals.

● *Citizen Advocacy (CA) for People with a Mental Handicap*

The descriptive phase of this research involves a review of the experience of CA projects in Wales set against UK and international perspectives. The evaluation phase has begun with the detailed study of a hospital-based CA project.

● *Psychiatric Hospital Closure*

This multidisciplinary study seeks to evaluate the impact of hospital closure on the lives of long-stay residents, staff and, where relevant, informal supporters, concentrating on economic costs and the effectiveness of alternative services.

● *Dementia and Adaptation in Support Networks*

Part one of a five-year investigation into the relationship between the onset of dementia and its impact on the adaptation of support networks has begun, concentrating on ascertained, sub-clinical and non-cases over time.

Outputs: Reports and papers for all projects are produced at regular intervals

October 1977–May 1994 (1989/90: £217,476)

1989 publications — page 173

UNIVERSITY OF YORK

Centre for Health Economics

Heslington, York YO1 5DD (0904 433646 FAX 0904 433644)

5.22. Director: Professor A K Maynard

Financed by both the ESRC and DH, CHE conducts research on economic aspects of health and personal social services.

● *Care for People with a Mental Handicap*

With Dr N Raynes (Manchester University — 5.128, page 122), this study is investigating the relationship between costs, size and quality of residential homes for people with a mental handicap.

Outputs: A series of articles is being prepared during 1990

● *Communication Aids Centres*

This is an evaluative study, undertaken with Professor Chamberlain (Leeds University — 5.174, page 131), of six specialized Centres; a sample of users was undertaken over the period 1987–90.

Outputs: Main report due in 1990; articles to be published in 1991

● *Survey of Residential and Nursing Homes*

Data from a survey of private and voluntary homes, carried out in 1986/87, were analysed (with PSSRU — 5.7, page 89) in reports covering costs and charges, characteristics of homes and residents, staffing and managing ownership.

Outputs: A composite report is currently being prepared

● *The NHS and its Customers*

The range of quality assurances and management initiatives in the NHS have been reviewed in this project.

Outputs: Reports have been circulated; articles to be published during 1990/91

● *HIV, ARC and AIDS: Social Care and Provision*

Article — page 17

This four-tier study (with Professors Robinson and Smith — 5.72, page 110) includes the social care needs of people with HIV/ARC/AIDS and their carers, and the development of social care provision, with a detailed study of provision in five localities and of financial inputs.

Outputs: Report due in June 1990

● *Measurement and Valuation of Health*

This programme involves a methodological development of the measurement and valuation of health outcomes. It will retest previous methods, and test applications in the evaluation of clinical and other therapeutic interventions.

● *Economics of Alcohol Abuse*

This has been a critical review of the uses made of data on alcohol consumption, to evaluate how existing and new sources could be used more effectively.

Outputs: Report submitted to DH in 1989; articles to be published in 1990/91

● *Skill-Mix and the Effectiveness of Nursing Care*

This project aims to relate differences in the mix of nursing skills to the quality of patient care.

Outputs: Main report due in July 1990

● *Community Nursing (with SPRU — 5.23, page 100)*

A study to identify how HAS currently fix their community nursing establishments and to make recommendations for the future.

Outputs: Main report due in October 1992

October 1971–September 1995 (1989/90: £365,199)

1989 publications — page 173

UNIVERSITY OF YORK

Social Policy Research Unit

Heslington, York YO1 5DD
(0904 433608 FAX 0904 433618)

5.23. Director: Dr S Baldwin

Article — page 78

SPRU is jointly funded by the Departments of Health and Social Security to carry out research which straddles the social care–social security divide. This entry deals with projects funded by DH. The Unit's current programme of work for DH customers focuses on informal and community care, and contains four elements: the needs of informal carers and the effectiveness of services to support them; work on disability; the evaluation of specific services; and assessment for, and financial arrangements in, independent sector residential and nursing homes (with DSS).

● *Services in Support of Carers*

This is a qualitative study, in two local authority areas, of carers' and service providers' views on the provision of support.

Outputs: Report due in December 1990

● *Non-Elderly Spouse Carers*

A qualitative study of non-elderly carers looking after a disabled or chronically ill spouse, covering the financial impact of disablement and caring, and effects on children and marriages.

Outputs: Reported in June 1989; book in preparation

● *Secondary Analysis of GHS Data on Informal Care*

In this project, data from a special section on informal care (included in the 1985 GHS) are being analysed to develop a typology of caring, evaluate the impact of care-giving, examine service substitution, and describe the characteristics of male and spouse carers.

Outputs: Four working papers are being prepared

● *National Survey of Young People with Disabilities*

A follow-up survey of 13–22-year-olds in the OPCS disability surveys, to compare the circumstances of young disabled people with those of a control group and to consider the implications for services and formal support.

Outputs: Two working papers available; overview due in 1990

● *Incontinence Training Packages*

This is an evaluation of three training resources for incontinence, developed within the *Helping the Community to Care* initiative and intended for sufferers, informal carers, professional carers in the community, training establishments and paid and voluntary carers.

Outputs: Reported in 1989; articles have been published

● *Telecommunication Needs of People who are Deaf*

A quantitative and qualitative study of severely deaf people's telecommunications needs, and the perceived benefits of their access to new telephone services based on text.

Outputs: Final report and video of findings due in 1990

● *Research on Community Nursing (with CHE — 5.22, page 99)*

This is a study to identify how HAs currently fix their community nursing establishments and to make recommendations for the future.

Outputs: Final report due in October 1992

April 1976–September 1993 (1989/90: £302,000)

1989 publications — page 174

B. Programmes and Projects

Acute Sector Hospital-Based Services

BRITISH CARDIAC SOCIETY

7 St Andrew's Place
Regent's Park
London NW1 4LB
(071 486 6430)

5.24. Director: Dr E Sowton

Randomized Trial of Coronary Angioplasty Versus Bypass Grafting (RITA)

This randomized trial has been sponsored by the British Cardiac Society to assess results in Percutaneous Transluminal Coronary Angioplasty (PCTA) compared with bypass grafting in patients with coronary artery disease.

The study includes 1,600 patients suitable for treatment by either PCTA or coronary artery bypass grafting. Both groups are being closely followed, with data acquisition every three months. Sixteen centres capable of randomizing 100 patients each year have been selected to participate. End-points include death, new myocardial infarction or new invasive procedure. Assessment also includes procedural costs, hospital stay, time off work, and persisting levels of disability from angina.

A full register of every patient investigated at the participating centres during the recruitment period (two years) is being kept in order to identify how representative the RITA sample is. This register will provide unique data for future financial planning.

September 1988–December 1990 (1989/90: £98,249)

CENTRAL PUBLIC HEALTH LABORATORY

61 Colindale Avenue
London NW9 5HT
(081 200 4400)

5.25. Director: Professor E M Cooke

Methods of Surveillance of Hospital Infection

The study aims primarily to develop a simple, efficient surveillance method for hospital infection, the validity and reliability of which have been assessed, and which can be used to measure the incidence of infection in six selected hospitals.

The surveillance tool is intended to be used by Infection Control Nurses (ICNs) as one component of an infection control programme, as well as to evaluate selected nursing interventions in the prevention of infections.

During the first stage, a survey was carried out to establish a database on the most frequently used and efficient surveillance methods being used by ICNs. From that database, a 'Gold Standard' surveillance method has been established and a surveillance tool developed. In the second stage, this is being tested against the Gold Standard.

September 1987–August 1990 (1989/90: £23,161)

CLINICAL ACCOUNTABILITY, SERVICE PLANNING AND EVALUATION (CASPE)

King Edward's Hospital Fund

14 Palace Court
London W2 4HT
(071 229 8739 FAX 071 727 7603)

Research Director: Dr I Wickings

Associate Director: Mr J Coles

CASPE's programme of research aims to improve the quality and effectiveness with which NHS services are delivered, as a result of improved information and managerial systems.

5.26. *Brighton HA: the Development of Indicators of Medical Care Quality*

The objectives of this study include establishing a productive environment for developing new indicators of the quality of care, making an early assessment of their value to clinicians, and making practical recommendations for their economical implementation at local level. Four different approaches have been tested.

5.27. *Bloomsbury HA: Using Patient Satisfaction Indices to Influence Standards of Care*

This research has focused on developing routine, economical methods to monitor patients' satisfaction with the services they have received. The project has covered major areas of care in the acute setting, where patients are able to respond independently and confidentially.

5.28. *Developing Patient Satisfaction Indices for the new NHS*

The initial work in this area, undertaken at Bloomsbury, is now being field-tested at six other sites throughout England. It aims to determine whether the early findings are replicated in other authorities, and to identify differences in the way the system is used by managers.

5.29. *Newcastle HA: Development of Clinical Outcome Indicators*

This project is a feasibility study, aiming to establish ways of monitoring the short-term clinical outcomes of hospital care. Its objectives are to develop an approach that is acceptable to clinicians, and to identify features within that approach which are relevant across specialities and hospitals.

5.30. *Evaluation of Severity-Adjusted Diagnosis-Related Groups (DRGs)*

CASPE has carried out detailed studies of the DRG classification for DH and health authorities. This study examines the potential of refined DRGs for use within the NHS, focusing on those areas found to be problematic — either on statistical or clinical grounds — in the original classification.

5.31. Nursing Workload and its Relationship to DRGs

This project is investigating the relationship between acute care case-mix groups, as defined by DRGs, and nurse workload measures. The study takes a structured approach to investigating a number of existing nurse management systems, comparing their use and robustness across districts. Patient activity data will be assigned to DRGs and correlation between the two systems examined; the causes of variability will also be identified, and predictive models developed for prospective testing.

January 1979–December 1993 (1989/90 programme grant: £349,780)

KING'S FUND CENTRE

126 Albert Street
London NW1 7NF
(071 267 6111)

5.32. Director: Dr C Shaw

Clinical Audit Research

Using questionnaires and workshops, the project seeks to establish a means of both monitoring and promoting the growth of hospital audit in England and Wales, and to identify the current state of regional audit initiatives, future regional plans, and knowledge of initiatives at district level.

The research then aims to compile a basic data-set of general surgery audit, to enable comparison between authorities and encourage take-up of the data-set. Different approaches to audit are to be identified, and factors which facilitate or hinder the process will be examined.

January 1989–December 1990 (1989/90: £22,867)

MEDICAL RESEARCH COUNCIL

MRC Biostatistics Unit

20 Park Crescent
London W1N 4AL
(071 636 5422)

5.33. Director: Dr S McDonald-Gore

Inter-Regional Confidential Audit of All Deaths in Non-Neonatal Intensive Care Units

This is an audit of all deaths in non-neonatal, non-CCU only, intensive care units to compare, between regions, proportions of patients in whom brain-stem death was a possible diagnosis; who fulfilled criteria for brain-stem death; who were donors of their kidney only; and those who were multi-organ donors of suitable organs.

Possible explanations of inter-regional variation in organ donation are age, sex, cause of death, distribution of the deceased, omission of brain-stem death tests, whether the patient was discussed with the transplant team or coordinator, general medical contra-indication to organ donation, logistical impediments. Ethnicity is not examined in the first audit year.

February 1989–March 1991 (1989/90: £7,693)

NORTH EAST THAMES REGIONAL HEALTH AUTHORITY

Hampstead Health Authority

Royal Free Hospital School of Medicine
Department of Clinical Epidemiology and General Practice
Rowland Hill Street
London NW3 2PF
(071 794 0500 x 4293)

5.34. Director: Professor A G Shaper

British Regional Heart Study

The Regional Heart Study aimed to provide information on the causes of ischaemic heart disease, stroke and hypertension and to explain regional variations in cardio-vascular disease mortality in Great Britain, providing a unique national resource on cardiovascular disease in Great Britain.

Middle-aged men (n = 7,735) drawn at random from general practices in 24 towns in England, Wales and Scotland were examined and monitored for cardio-vascular morbidity and mortality over eight years. The relative importance of risk factors for ischaemic heart disease, both established (total cholesterol, smoking, blood pressure) and suspected (HDL-cholesterol, alcohol, cadmium, personality, family history) were evaluated. Stored serum was used for case-control studies of apoproteins, coagulation factors and fatty acid patterns in ischaemic heart disease. A study of blood pressure in children pursued the marked between-town blood pressure differences in adult men. Relationships between unemployment and ischaemic heart disease were explored using a questionnaire at five years.

October 1985–September 1992 (1989/90: £14,854)

NORTH WEST THAMES REGIONAL HEALTH AUTHORITY

Riverside Health Authority

Charing Cross Hospital
Department of Medical Oncology
Fulham Palace Road
London W6 8RF
(081 846 1234)

5.35. Director: Professor K D Bagshawe

The Evaluation of Tumour Markers

The objective of the programme is to evaluate the contribution of serological tumour markers to the clinical care of patients and to relate this to the overall costs incurred in providing marker measurements.

A series of studies, each focusing on one particular type of cancer, are being carried out. The first three studies are: colorectal cancer with reference to Ca-50, Carcinoembryonic Antigen (CEA) and possibly Ca19-9; ovarian cancer with reference to Ca-125, Placental Alkaline Phosphatase (PLAP), CEA, Human Milk Fat Globule membrane antigen (HMFG) and a new urinary marker identified in this laboratory (AKP3); and prostate cancer, with special reference to Prostate Specific Antigen (PSA). Other studies being considered include cancer of the breast, lung, stomach, pancreas, and cervix, and squamous cell carcinomas at other sites.

Although the main area of application of markers is in monitoring the course of malignant diseases, they may have a role in primary diagnosis. Some of the studies will evaluate this role.

October 1987–December 1990 (1989/90: £92,840)

OXFORD REGIONAL HEALTH AUTHORITY

West Berkshire Health Authority

Royal Berkshire Hospital
Craven Road
Reading
Berkshire RG1 5AN
(0734 861957)

5.36. Director: Dr A Watson

The Incidence of Leukaemia in West Berkshire

This project is designed to investigate the possible increased incidence of childhood leukaemia in the West Berkshire and Basingstoke and North Hampshire District Health Authorities. In particular, it aims to determine if there is any association between childhood cancer and parental employment in the nuclear establishments in the study area.

The study is of a case-control design. The cases comprise all children under 15 years of age first diagnosed as having cancer between the years 1972 and 1988. An interview administered questionnaire is being used to collect information from the parents of the cases and their matched controls. Occupational and residential data are being validated wherever possible.

October 1987–December 1990 (1989/90: £39, 945)

QA BUSINESS SERVICES LTD

Management Services Division

326 High Street
Harborne
Birmingham B17 9PX
(021 426 1050)

5.37. Director: Mr P Clare

The Efficiency of Hospital Waiting-List Systems

The aim of the project is to produce guidelines on the administration of hospital in-patient waiting-lists. A postal survey of hospitals in England is being undertaken to ascertain the current range of waiting-list systems and administrative practices used in the eight main surgical specialities.

The survey sample comprises all acute units having 250 beds or more — some 260 hospitals. Detailed investigations are being carried out at 12 participating hospitals to check their responses, to assess the quality of their waiting-list administration, and to establish the role of hospital managers. Measures of administrative performance will be developed to facilitate this assessment.

Draft guidelines developed as a result of this research will be discussed with each of the 12 hospitals to obtain the views of potential users, and the report finalized and made available for issue to the NHS. It will include the results of the national survey, showing the extent to which hospitals do or do not already conform to the recommendations.

September 1989–August 1990 (1989/90: £11,040)

ROYAL COLLEGE OF GENERAL PRACTITIONERS

Manchester Research Unit

8 Barlow Moor Road
Manchester M20 0TR
(061 445 7771)

5.38. Director: Dr C Kay

Attitudes to Pregnancy Study

The objective of the study is to monitor the long-term effects of induced abortion.

Approximately 6,000 women who have had an induced abortion are included in the study and are being compared with a control group of nearly 12,000 women who had an unplanned pregnancy which was continued to term.

Endpoints of the study are reproductive efficiency, including fertility and the effect on the outcome of any subsequent pregnancy, and mental sequelae. All other reported morbidity and mortality has been recorded.

June 1973–December 1990 (1989/90: £166,655)

ROYAL COLLEGE OF NURSING

Institute of Nursing

Radcliffe Infirmary
Woodstock Road
Oxford OX2 6HE
(0865 816833)

5.39. Director: Dr A L Kitson

Standards of Care

This project seeks to evaluate a planned programme for setting, maintaining and evaluating standards for nursing care in nine acute general medical or surgical wards in three DHAs. The study focuses on the educational aspects of the programme and is concerned with the way ward staff respond to the task in each of the nine wards. It will also evaluate staff reactions and patient experiences of care both before and after the introduction of the planned programme.

Staff are to be given one patient care topic, for example, discharge planning, on which to write their first standard. Information about patient outcomes and nursing actions is to be gathered both before and after the standard setting exercise. Finally, the data collected on all three topics will be compared in order to evaluate the impact of the programme.

January 1989–December 1991 (1989/90: £39,040)

ROYAL POSTGRADUATE MEDICAL SCHOOL

Hammersmith Hospital

Du Cane Road
London W12 0HS
(081 743 2030)

5.40. Director: Professor Sir Colin Dollery

DH Hypertension-Care Computer Project

The DH Hypertension-Care Computer Project (DHCCP) is a longitudinal study of hypertensive patients who have been followed-up during the period 1971–1987 at five hospital centres. The current database contains records of some 11,000 patients and 1,200 deaths. All patients are registered with the OPCS and mortality data will continue to accrue.

The major aims of the project are to determine the factors associated with survival in healed hypertensive patients, both overall and in special subgroups such as the elderly or women, and to examine the effects of treatment — especially newer classes of drugs — in terms of mortality and morbidity, side effects, toxicity and effect on 'quality of life'.

June 1989–May 1992 (1989/90: £16,908)

SOUTH WEST THAMES REGIONAL HEALTH AUTHORITY

Chichester Health Authority

Royal West Sussex Hospital
St Richard's Branch
Spitalfield Lane
Chichester
West Sussex PO19 4SE
(0243 788122)

5.41. Director: Mr R A P Scott

Routine Ultrasound Screening in the Management of Abdominal Aortic Aneurysm

Rupture of an abdominal aneurysm is responsible for 1.3 per cent of all deaths in men over 65 years of age — many of these deaths are premature and avoidable. Most patients who rupture an aneurysm die before they can be offered surgery and, in the remainder, operative mortality is 50 per cent. By contrast, elective surgery for abdominal aortic aneurysm has an operative mortality of less than 5 per cent and patients who survive surgery enjoy a normal life expectancy. It follows that early detection of abdominal aneurysms and elective surgery before rupture occurs could save many lives.

The aim of this research is to screen the high risk population of men between the ages of 65 and 75 years, by clinical and ultrasound examination of the aorta. Patients with substantial aneurysms will be offered elective vascular surgery, while those with smaller aneurysms will be reviewed to determine aneurysm growth rates and risks of rupture.

March 1989–December 1993 (1989/90: £46,631)

UNITED KINGDOM TRANSPLANT SERVICE

South West Regional Transfusion Centre

Southmead Road
Bristol BS10 5ND
(0272 507777)

5.42. Director: Professor B A Bradley

An Investigation into the Factors Affecting the Outcome of Corneal Transplants in the UK

The purpose of the study is to quantify those factors that influence the success of corneal transplants by studying pre-operative and post-operative events. Discrete time intervals during the post-operative period have been examined to ascertain when factors exert their maximum effect.

This has been done by the use of multifactorial statistical techniques which have been adapted from the analysis of renal transplant follow-up data. Thus early and late acting factors have been identified, allowing clinicians to judge for themselves which procedures give better results. By comparing an individual centre's experience with pooled national data, clinicians will be able to assess how their practices differ from those of their colleagues.

The completion of the study means that The United Kingdom Transplant Service is able to improve the scientific basis on which the Corneal Transplant Service rests, to assist in the planning of future resource allocations, and, in the long term, to reduce the risk of premature graft loss in corneal transplant recipients.

July 1986–January 1990 (1989/90: £4,253)

UNIVERSITY OF BRISTOL

Institute of Child Health

Royal Hospital for Sick Children
St Michael's Hill
Bristol BS2 8BJ
(0272 215411 x 5231)

5.43. Director: Dr A Emond

Avon Perinatal Follow-up Study

This is a population study in Avon of the outcome of perinatal events and their relationship to social and environmental factors. It entails the prospective community based follow up of high-risk, preterm (born seven or more weeks too early) babies, together with two control groups of normal birthweight babies.

Prospective data are being collected on perinatal events, maternal stress and depression and social circumstances. Outcome is to be assessed in terms of illness in infancy, neurodevelopmental delay, behavioural problems and family disruption. The incidence of miscellaneous acute health problems and the pattern of use of primary care facilities is to be derived using a 'Passbook to Health' book in which every contact with health agencies is being recorded.

The purpose of the study is to define how medical and environmental factors associated with high risk babies affect

their health, and to indicate how services can be optimally deployed to meet the needs of these children and their families. The study is jointly funded by DH, the DoE, the Spastics Society and South West Regional Health Authority.
January 1988–December 1990 (1989/90: £9,655)

BRUNEL UNIVERSITY

Health Economics Research Group

Uxbridge
Middlesex UB8 3PH
(0895 56461 x 289)

5.44. Director: Dr M J Buxton

Medical Evaluation of Special Medical Development Screening for Diabetic Retinopathy

The study was based in three centres — Exeter, Oxford and Sheffield — and assessed alternative methods for screening diabetics to detect treatable diabetic retinopathy. The methods considered were GPs, and non-mydriatric photographs assessed by a consultant ophthalmologist (all 3 centres); ophthalmic opticians (Oxford), and diabetic physicians (Exeter). Using an Ophthalmological Clinical Assistant (OCA)'s fundal assessment for each case, the sensitivity and specificity of these methods were assessed.

A second phase of the project examined the incidence of the disease by re-screening diabetics a year after initially visiting the OCA. The resource cost implications of the various methods were considered, using considerable data collected on lengths of screening sessions, staff involved and numbers of patients. Those costs falling on patients in terms of travel and possible lost earnings were also examined.

October 1985–September 1989 (1989/90: £47,474)

5.45. Director: Dr M J Buxton

Resource Management Initiative: Evaluation of Pilot Sites in Acute Hospitals

The work reviews the impact of Resource Management on six pilot hospital sites and examines in detail the experience of two sites — Newcastle and Winchester.

Costs include both the direct and indirect costs associated with Resource Management, and benefits include the process outputs, behavioural changes, service outcomes and improvements in patient care that result.

The research is divided conceptually into two stages involving the identification of appropriate indicators of costs and benefits and their subsequent measurement, together with a comparison of outcomes achieved with resources used.

April 1988–March 1991 (1989/90: £89,534)

5.46. Director: Dr M J Buxton

An Initial Assessment of the Cost-Effectiveness of Automatic Implantable Cardioverter–Defibrillators (AICDs)

A small-scale, exploratory cost-effectiveness analysis of AICDs, this study aimed to identify the resources used in AICD cases in the UK, and to relate their costs to available information on patients' survival and quality of life.

Data on this new technology were gathered from current British, American and European literature, and from the records of the very few patients so far who have AICDs.

January 1989–April 1989 (1989/90: £6,000)

UNIVERSITY OF CAMBRIDGE

Department of Community Medicine

Level 5
Addenbrooke's Hospital
Hills Road
Cambridge CB2 2AQ
(0223 336810)

5.47. Director: Dr M Rowland

Maintaining Donors for Organ Transplantation: An Assessment of the Costs

This was a national survey involving a questionnaire to all centres providing donor organs. Data on the resources involved in a sample of individual donor cases were collected and analysed.

The aim of the work was to provide information about possible reimbursement policy, following the report of a working party on the supply of donor organs for transplantation (DHSS 1987).

February 1988–July 1989 (1989/90: £447)

UNIVERSITY OF LEEDS

Nuffield Institute for Health Services Studies

71–75 Clarendon Road
Leeds LS2 9PL
(0532 459034)

5.48. Director: Mr G Wistow

The Hospital In-Patient Night

This project aims to supplement the Management Consultancy Services (MCS) study of night nursing services by addressing three central issues: both the patient's and the nurse's perspectives on how care is organized and might be improved; and nurse managers' perspectives on barriers to changing the organization of night nursing services.

Data are being collected using questionnaire surveys and interviews with patients and nursing staff in three large District General hospitals. All night nursing staff and random groups of day nurses from sample wards are to be interviewed. The information collected will be used to improve policies on the organization of the hospital in-patient's night.

November 1989–September 1992 (1989/90: £2,981)

UNIVERSITY OF LIVERPOOL

Department of Community Health

PO Box 147
Liverpool L69 3BX
(051 709 6022 x 2180)

5.49. Director: Professor P O D Pharoah*The Costs and Benefits of Neonatal Intensive Care*

This study is comparing a geographically-defined cohort of very low birthweight infants (less than 1500g) together with a sample of low birthweight infants (1501 to 2500g) with a matched sample of infants of normal birthweight (more than 2500g).

For this purpose, a series of psychometric tests to determine the prevalence of both major and minor impairments is being used. A comparison is also being made of major disability in two cohorts of very low birthweight infants from before and after the introduction of neonatal intensive care.

A costing of neonatal intensive care is subsequently to be linked to a detailed costing of health and social service usage, which is associated with impairments in the children. Conversion of the data to streams of costs after discounting will allow the costs of various outcomes to be compared.

February 1988–January 1991 (1989/90: £26,620)

Department of Nursing

Senate House
PO Box 147
Liverpool L69 3BX
(051 794 2306)

5.50. Director: Dr K Luker*Development and Evaluation of Assisted Learning for Patients on Continuous Ambulatory Peritoneal Dialysis (CAPD)*

Patients experience many problems in learning to live with CAPD in the treatment of end-stage renal disease. A more systematic approach to patient teaching would improve patients' understanding of their condition and reduce the incidence of problems of both a physical and psycho-social nature.

The aim of the study is to develop and evaluate computer-assisted learning programmes for these patients. Six 15-minute programmes are proposed for use on the BBC 'Master' computer, using microtext. These programmes are being evaluated using a matched-pair experimental design. The dependent variables are: patients' knowledge and understanding of their medical condition; psycho-social well-being, which is measured using Lishman's (1972) mood adjective checklist; and incidence of complications — for example, peritonitis.

To complete the evaluation, structured interviews are being carried out to elicit the opinions of the nurses and patients who have been involved with computer-assisted learning. In this way, a comprehensive evaluation of computer-assisted learning in this patient group will be provided.

March 1988–February 1991 (1989/90: £29,204)

UNIVERSITY OF LONDON

Institute of Child Health

Great Ormond Street Hospital
30 Guilford Street
London WC1N 1EH
(071 242 9789 x 8)

5.51. Director: Professor M A Preece*Patients Treated with Human Growth Hormone of Pituitary Origin*

This project involved following up about 2,000 children in the UK who had been treated with Human Pituitary Source Growth Hormone (HGH) since 1959. The children's GPs were traced through the OPCS and then through the NHS Central Register, and were asked to complete a questionnaire concerning the current health of their patients with particular reference to neurological symptoms.

The aim of the project was to establish the presence or absence of any indication of neurological disease amongst these patients.

October 1987–September 1989 (1989/90: £2,817)

5.52. Director: Dr I Smith (071 242 9789)*Phenylketonuria Register*

Phenylketonuria (PKU) consists of a group of inherited disorders which lead to the accumulation of phenylalanine — an essential amino acid present in all proteins. Severe mental retardation develops in a high proportion of children with PKU unless treatment with a phenylalanine-low diet is introduced in early infancy.

The PKU Register was set up in 1964 to determine whether early treated children could achieve normal development. The positive findings influenced the decision to implement neonatal screening in 1969/70; and the Register undertook to audit the programme in terms of coverage, 'missed' cases, implementation of treatment and psychological outcome. Testing for congenital hypothyroidism — another cause of preventable retardation — was added to this programme in 1982, and when it became clear that the unborn children of women with PKU were at risk, a study of pregnancy outcome was established.

Currently, the PKU Register is examining the social adjustment and physical health of young adults, including the risks to neurological integrity of relaxing or stopping treatment.

September 1977–April 1990 (1989/90: £32,726)

The Rayne Institute

University College
University Street
London WC1E 6JJ
(071 388 2411 x 269)

5.53. Director: Dr A Stewart*Neurodevelopmental Disorders in Newborn Infants who Require Intensive Care*

The introduction of intensive care methods such as mechanical ventilation for ill newborn infants has resulted in a

substantial fall in mortality. However, a proportion of the survivors are found later to have neurodevelopmental disabilities, some of which are severe.

The availability of objective techniques for assessing brain structure and function (for example ultrasound scanning, brain-stem and visually-evoked potentials, **magnetic resonance** spectroscopy and near infra-red spectrophotometry) allows potentially brain-damaging lesions to be detected in the first days of life.

This project, jointly funded with the MRC, investigates how these lesions affect neuropsychological outcome in childhood and aims, additionally, to derive predictive indices for outcome which can be applied to other newborn infants undergoing intensive care.

October 1986–September 1991 (1989/90: £69,958)

UNIVERSITY OF NOTTINGHAM

Department of Medicine

D Floor, S Block

Queen's Medical Centre

Nottingham NG7 2UH

(0602 700111)

5.54. Director: Professor J Hampton

Nottingham Heart Attack Register

A register of all patients with heart attacks in Nottingham has been maintained with DH support since 1982, providing the basic epidemiological background against which the cost and effectiveness of new forms of treatment can be assessed.

The national mortality rate from ischaemic heart disease in the United Kingdom seems to be beginning to fall, although it is not clear whether this reflects a change in case-fatality rates or a change in disease prevalence. The Nottingham register will show whether there have been any changes, over time, in the case-fatality rate in Nottingham, and will help to identify the causes of national changes.

Specifically, the Nottingham register has been established to help evaluate the effect of introducing a defibrillator-equipped emergency ambulance service. Over the next few years, however, the most immediately important use of the register will be to help determine the costs and benefits of the widespread introduction of thrombolytic therapy for patients with suspected heart attack.

August 1988–July 1991 (1989/90: £31,393)

UNIVERSITY OF OXFORD

Oxford Orthopaedic Engineering Centre

Nuffield Orthopaedic Centre

Headington

Oxford OX3 7LD

(0865 64811)

Acting Director: Dr A R Turner-Smith

The Centre undertakes basic investigative studies of musculo-skeletal physiology and of the mechanical factors involved in orthopaedic conditions and treatment.

5.55. *Prosthetic Joint Loosening*

Movement of prosthetic joint components within the bone may take the form of loosening or long-term migration: both movements lead to the ultimate failure of the implant. This research is developing three basic techniques — X-ray photogrammetry, vibration analysis and acoustic emission — for measuring hip prosthesis loosening.

5.56. *Two Prosthetic Foot Mechanisms in Below-Knee Amputees*

This study was undertaken to identify functional biomechanical differences between the 'Quantum' foot — a compliant design — and the 'Multiflex' — a multi-axial joint design, and to attempt to establish scientific criteria for their prescription. Subjective and quantitative measures were made using a questionnaire and by analysing data from a televised gait-analysis system.

5.57. *The Function and Properties of Metatarsal Domes*

Ten control subjects and 15 rheumatoid patients were investigated to show the change in the regional pressures for each dome; pressure distribution was characterized across the metatarsal heads using the pressure under three regions. A significant difference in regional pressure patterns and their changes was observed between patients and the control group, but no statistically significant difference was detected between the domes ($p = 0.21$).

August 1974–September 1989 (1989/90 programme grant: £131,331)

UNIVERSITY OF SHEFFIELD

School of Clinical Dentistry

31 Claremont Crescent

Sheffield S10 2TA

(0742 766222)

5.58. Director: Dr C Douglas

Control of Micro-Organisms in Dental Water Supplies

The progression of micro-organisms in the water supply to the instruments on a dental unit is a potential source of cross infection in the dental surgery, particularly for immuno-compromised patients.

Many of the new generation of dental units now being manufactured incorporate a decontamination system. For older dental units, however, a simple device enabling the sustained release of an anti-microbial agent has been developed. This is inserted into the water supply line and has been shown to keep one dental unit free from micro-organisms for three months.

The purpose of this study is to determine the effectiveness and reliability of the device by carrying out a more extensive user trial in a dental hospital.

September 1989–June 1990 (1989/90: £2,036)

UNIVERSITY OF SOUTHAMPTON

Highfield

Southampton SO9 5NH

(0703 559122)

5.59. Director: Dr R Davies*Simulation Planning model in Cardiology*

Management of coronary disease is an expensive health care system for which realistic budgets are required and for which development of a discrete event simulation model is appropriate. The cardiology, finance and medical planning departments at Guy's Hospital collaborated in the development of such a technique.

During the project, a microcomputer simulation model was devised, tested and validated in conjunction with medical staff. Reports which can be used together with developing budgetary systems and database designs were produced. The modelling technique is particularly successful in allowing doctors and managers to control how the model is used and what assumptions are made in operating it. It will be possible to develop work completed during this project in other cardiology departments and in other hospital specialities.

September 1986–December 1989 (1989/90: £11,195)

UNIVERSITY OF WALES

College of Medicine

Heath Park
Cardiff
Wales CF4 4XN
(0222 755944)

5.60. Director: Professor P S Harper*Recombinant DNA Studies in the Diagnosis of Inherited Neurological Disorders*

Funding was allocated to the Institute of Medical Genetics in 1984 to enable the systematic application of recent advances in technology to the diagnosis of inherited neurological disorders.

A DNA diagnostic service (DNA is the chemical of which genes are composed) has been set up, allowing more informed genetic counselling and more reliable risk prediction. The research also involved the mapping and isolation of genes for serious neurological disorders.

This project was carried out in conjunction with sister projects at the Department of Medical Genetics, University of Manchester, and at the Mothercare Department of Paediatric Genetics, Institute of Child Health.

January 1985–March 1989 (1989/90: £5,707)

Institute of Medical Genetics

Heath Park
Cardiff CF4 4XN
(0222 755944)

5.61. Director: Professor P S Harper*Recombinant DNA and the Prevention of Inherited Neurological Disease*

Inherited neurological disorders are responsible for a major proportion of chronic disability and early mortality in both adult life and childhood. As there has been relatively little progress in understanding the pathogenesis of these disorders and in devising approaches to prevention and therapy, these condi-

tions have for some years occupied a prominent position in genetic counselling services, but such counselling, while valuable, has been limited by the absence of predictive tests for the genes involved.

The development of recombinant DNA techniques and their application to the gene-mapping of genetic disorders has radically changed the possibilities for the prevention of these neurological disorders. So far, such advances have been considered in context of individual conditions; this project aims to document the likely impact of their overall contribution to the prevention of inherited neurological disorders.

April 1989–March 1992 (1989/90: £40,467)

Nursing Research Unit

School of Nursing Studies
College of Medicine
Heath Park
Cardiff CF4 4XN
(0222 755944 x 2942)

5.62. Director: Professor J M MacGuire*The Development of Primary Nursing Care in Wales*

This project has four main objectives: to determine how widespread task allocation, team nursing, patient allocation, and primary nursing are as methods of organization; to determine whether this typology is comprehensive, and whether more than one method is used in any one setting; to describe examples of primary nursing or other initiatives in the organization of care; and to consider whether, and how, the spread of primary nursing and other initiatives might be facilitated.

In phase one, a census is being taken of all wards, departments and community sectors in every NHS district in Wales. In phase two, initiatives will be listed and case studies of up to 20 will be undertaken.

The findings of the study will be used to inform the Welsh Office about the extent of current innovations, and the feasibility of their wider introduction.

November 1989–October 1991 (1989/90: £3,830)

Welsh School of Pharmacy

Institute of Science and Technology
PO Box 13
Cardiff CF1 3XF
(0222 874000 x 5826)

5.63. Director: Dr S Thomas*Evaluation Techniques for New Wound Healing Devices and Similar Appliances*

The availability of wound management products within the NHS requires their inclusion in the Drug Tariff. The aim of this project is to determine the clinical nursing and community criteria required for a product, and to identify those biological, chemical and physical factors which manufacturers should document in submitting a product for inclusion. The resulting guidelines will benefit both manufacturers and DH, and subsequently both patient and clinician.

November 1988–October 1990 (1989/90: £25,148)

UNIVERSITY OF WARWICK

Department of Sociology

Coventry CV4 7AL
(0203 523523)

5.64. Director: Professor M Stacey

Overview of Research on the Provision and Utilization of Child Health Services

In April 1984, DH commissioned a six-month project to review published and ongoing research into the provision and utilization of pre-school and school child health services. The aim was to identify those areas where further research was needed.

Provision of service has been taken to cover both what is provided and how it is done. School health service research, research into adolescent health services and child psychiatry have been examined, as has the identification of handicap and screening for genetic disease. The overview covering the period January 1980 to July 1984 was published in January 1987 and consisted of an index of publications and research in progress, an annotated bibliography and a final assessment of the overview. Following this study, an update (January to December 1987) was published in April 1989.

In 1986, the Department commissioned a similar overview of research on the care of children in hospital. This covered the period 1976 to 1986 and was published by the University of Warwick in 1989. Further updates of both documents are planned.

August 1986–July 1992 (1989/90: £6,142)

Health Services Research Unit

Coventry CV4 7AL
(0203 523523)

5.65. Director: Mr J A Stilwell

The Evaluation of Tumour Markers

The programme is integral with one supported by the Cancer Research Campaign (CRC). **Reagents** — principally antigens and antibodies, but possibly including growth factors and receptors, and the synthesis of peptides — are to be produced for use in the diagnosis and monitoring of malignant disease, immunoscintigraphy and targeted therapy.

Its primary direction will be towards targeted therapy, using rodents bearing human xenografted tumours and immunoscintigraphy as important tools to develop the clinical programme. Collaboration with other groups is helping to reduce potential microbiological hazards, the selection of targeted isotopes and enzymes and, where appropriate, to ensure the production of diagnostic and therapeutic agents.

Studies conducted to date have established the value of a 'second' antibody technique in increasing discrimination between tumour and non-tumour tissue through two distinct mechanisms. This opens a wide range of discrimination provided by tumour markers alone.

October 1987–September 1990 (1989/90: £7,433)

Nursing Policy Studies Centre

Health Services Research Unit
Coventry CV4 7AL
(0203 523523)

5.66. Director: Mr J A Stilwell

A Study of Decision-Making on Nursing Staff-Mix in Hospital Wards in Wales

The purpose of the project is firstly to investigate the complete decision-making process which leads to an observed pattern of 'who does what' on the ward. When the key decision areas have been identified, the outcome of these decisions in terms of quality of care and cost-effectiveness will be appraised, and the potential of management information systems for making improvements at three levels — service planning, operations, and direct patient care — will be studied.

The information needed for the research is to be gathered by examining decision-making at the service planning level using an interview study; at the operational level by means of both an interview study and a quantitative study of staff inter-ward allocation and day-to-day movements; and at the patient care level by means of an observational and interview study.

January 1989–April 1991 (1989/90: £51,182)

UNIVERSITY OF YORK

Department of Economics and Related Studies

Heslington
York YO1 5DD
(0904 430000)

5.67. Director: Professor A Culyer

Hospital Behaviour and Competition

This review aims to draw on European, Canadian and American experience to help identify the economic difficulties that might arise in the implementation of an NHS hospital provider market — such as potential abuse of monopoly power — and to indicate solutions. The study focuses on the practice of encouraging and regulating hospital competition in countries with reasonably tight financial regimes.

August 1989–December 1990 (1989/90: £1,000)

AIDS

ANGLIA COLLEGE OF HIGHER EDUCATION

Faculty of Health and Social Work

Danbury Park Management Centre
Danbury
Chelmsford
Essex CM3 4AT
(0245 412141/415511 x 235)

5.68. Director: Dr J A Akinsanya

Who Will Care? — A Study of the Knowledge, Attitudes and Clinical Decision-Making of Hospital Nurses towards AIDS Clients

This study investigates the current level of knowledge of a sample of practising hospital nurses and selected managers, as well as their attitudes and strategies in the care of clients with health problems related to AIDS. It focuses on three selected health authority areas in England with known problems of HIV/AIDS amongst the population and one health authority where there is virtually no known problem.

October 1988–December 1990 (1989/90: £25,522)

INSTITUTE OF PSYCHIATRY

Addiction Research Unit

De Crespigny Park
Denmark Hill
London SE5 8AF
(071 703 5411 x 3446)

5.69. Director: Mr A Glanz

Survey of Pharmacy Sales of Needles and Syringes

The study contributed to an understanding of the extent to which needle-sharing leads to the spread of HIV infection.

Data were gathered, through the postal survey of a stratified sample, on the current and potential involvement of community pharmacists in needle and syringe supply, and related activities.

September 1988–December 1989 (1989/90: £2,120)

NORTH EAST THAMES REGIONAL HEALTH AUTHORITY

Bloomsbury Health Authority

25 Grafton Way
London WC1E 6DB
(071 387 9300)

5.70. Director: Mr M Rees

AIDS Costing Study

Article — page 26

This three-part project identified average costs involved in the management of HIV-positive and AIDS patients.

The first part calculated the costs incurred in Riverside Health Authority, both in hospital and the community. The second part calculated the costs of HIV/AIDS provision in Oxfordshire and Brighton health authorities.

A follow-up study of three cohorts of patients diagnosed as having AIDS in 1984/85 is being undertaken to assess the flow of costs through time.

October 1986–September 1989 (1989/90: £21,681)

SOUTH WEST THAMES REGIONAL HEALTH AUTHORITY

Wandsworth Health Authority

St George's Hospital Medical School
Department of General Practice and Primary Care
Jenner Wing, Level O, Block G1
Cranmer Terrace
London SW17 0RE
(081 767 7697)

5.71. Directors: Professor P. Freeling, Dr B Sibbald
AIDS and Vocational Training in General Practice

Article — page 29

General medical practitioners have an increasingly important part to play in health education and health care provision for AIDS. How well future GPs meet this challenge depends in great measure on the nature and quality of their vocational training.

The aim of this project was to assess the need for additional learning and teaching about AIDS and HIV infection in GP training. The researchers carried out a postal questionnaire survey of the knowledge, attitudes and response to AIDS and HIV infection of trainees in general practice and their trainers: telephone interviews were used to expand questionnaire responses.

The findings will be used to identify those aspects, if any, where additional or alternative teaching for GPs is advisable.

January 1989–December 1989 (1989/90: £23,691)

UNIVERSITY OF HULL

UNIVERSITY OF YORK

Institute of Health Studies

Hull HU6 7RX
(0482 465966)

Centre for Health Economics

Heslington, York YO1 5DD
(0904 430000)

5.72. Director: Professor D Robinson (Hull)
Contacts: Professor G Smith (Hull), Professor A Maynard (York)

HIV, ARC and AIDS Needs for Social Services and the Development of Provision

Article — page 17

This investigation is concerned with the range and cost of HIV/ARC/AIDS-generated demands for social care, the management and coordination of that care, and the development of SSDs' patterns of provision.

The project has four parts: Firstly, the social care needs of those with HIV/ARC/AIDS and their informal carers are assessed, based on a cross-sectional survey and a small panel in four study localities. Secondly, the development of SSD provision for those with HIV/ARC/AIDS and their informal carers in the same four study localities is evaluated, based on interviews with key informants, analysis of reports and documents, and attendance at meetings. Part three reviews the development of SSD provision in England and Wales, based on a structured national survey, and lastly, the financial impact

of HIV/ARC/AIDS on those with the condition, and their informal carers, together with the resources needed to provide informal and formal social care, is evaluated.

April 1988–June 1990 (1989/90: £150,843)

UNIVERSITY OF LONDON

Birkbeck College

16 Gower Street
London WC1E 6DP
(071 631 6512)

5.73. Directors: Mr R Hartnoll, Dr A Johnson, Dr J Holland

HIV Prevention Outreach Project

The purpose of this study is to investigate ways of reaching and reducing HIV-related risk behaviour in hard-to-reach populations such as drug injectors, prostitutes and homeless young people, who are not effectively reached by existing prevention and health education measures.

In the first place, alternative models for contacting hard-to-reach populations and for reducing high-risk behaviour relevant to HIV infection are being reviewed. Secondly, an innovative outreach model of health education and risk reduction in Central London (CLASH—Central London Action on Street Health) is being evaluated.

The results are to be presented and discussed in the context of the wider review, and will focus on the possibility of using the outreach model of prevention in other districts.

March 1988–October 1990 (1989/90: £37,645)

Goldsmiths' College

Department of Sociology
London SE14 6NW
(081 692 7171)

5.74. Director: Dr G V Stimson

National Evaluation of Syringe-Exchange Schemes and HIV Risk Behaviour of Clients and Comparison Groups

This project follows up previous research on syringe-exchange schemes. Two studies are being undertaken.

The first assesses the development of exchange schemes, looking at their ability to reach and retain injecting drug users, service delivery and service organization and developments.

During the second study, clients from exchange schemes and comparison groups are to be followed up to examine short and long-term changes in HIV risk related behaviour. Factors affecting the schemes' ability to make and sustain behavioural change are also to be examined. In all, 90 exchange scheme clients and 90 injecting drug-users not in contact with schemes are being followed up over one year.

December 1988–November 1990 (1989/90: £145,548)

St Mary's Hospital Medical School

Department of Community Medicine
Praed Street
London W2 1PD
(071 723 1252 x 5607)

5.75. Director: Professor D Miller

Hospital Service Provision for People with AIDS and HIV Infection

The purpose of this study is to describe the services provided by Parkside District Health Authority for people with AIDS and HIV infections. An assessment is being made of the services used by the patients at each stage of the illness, from pre-test counselling through to terminal care. Hospital records are being scrutinized, and questionnaires completed by heads of departments and staff will allow an assessment of the HIV/AIDS workload. The costs of services used will also be estimated.

Two groups of patients are being studied: Group A consists of AIDS and ARC patients either receiving treatment in Parkside DHA at the start of the study, or deceased ($n = 375$); Group B comprises 100 patients with a positive test for antibodies to HIV, but without symptoms.

The findings of the study will assist the District, Region and Department of Health in the management, planning and improvement of services; in estimating the resources likely to be needed to meet future demands; and in improving routine data collection systems in order to monitor and provide for changes in service requirements.

October 1989–December 1990 (1989/90: £14,390)

UNIVERSITY OF WALES

Social Research Unit

University College
PO Box 78
Cardiff CF1 1XL
(0222 874396)

5.76. Director: Professor A Coxon

Contact: Dr P Davies

The Impact of AIDS on the Sexual Behaviour of Homosexual Males

The project examined the effects of AIDS and HIV infection on the sexual behaviour of homosexual men, particularly the uptake and spread of safer sexual practices.

A sample of over 900 homosexual and bisexual men was drawn from ten towns and cities in England and Wales; data were collected through interviews, questionnaires and diaries.

The project was carried out in conjunction with an MRC-funded study of seroprevalence and sexual behaviour among homosexual men.

January 1987–June 1989 (1989/90: £34,993)

UNIVERSITY OF WARWICK

Centre for Corporate Strategy and Change

Coventry CV4 7AL
(0203 523523)

5.77. Director: Professor A Pettigrew

Development of AIDS Services by DHAs: The Organizational Response to AIDS

Article — page 20

This project is a detailed comparative analysis of District Health Authority (DHA) responses to AIDS. Four DHAs or Health Boards are being studied, each having substantial experience of providing for HIV/AIDS patients. The whole spectrum of service provision will be covered in each district, focusing on hospital services for two districts and health promotion for the remaining two districts.

The research explores the impact of differing conditions, structural and cultural contexts, inter-organizational collaboration and strategies for change, on the pace and direction of development of HIV/AIDS services at local level. Districts are being studied separately, each undergoing a case-study lasting about three months. As each case-study finishes, feedback to the DHA will be in the form of a large case-study document, an executive summary and a workshop.

January 1989–June 1991 (1989/90: £48,371)

Child Care

BRITISH AGENCIES FOR ADOPTION & FOSTERING

11 Southwark Street
London SE1 1RQ
(071 407 8800)

5.78. Director: Ms J Rowe

Child Care Placement: Patterns and Outcomes

A comprehensive survey of all child care placements in six contrasting local authorities. The main aim is to provide basic information on the numbers and characteristics of children going into various types of placement and the outcome of these placements.

A descriptive study of the six authorities has been undertaken so that the statistical data may be put into context. Information has been obtained from social workers using pre-coded questionnaires, but there has been no contact with children, parents or care-givers. Around 95 per cent of questionnaires have been returned.

April 1983–March 1990 (1989/90: £12,244)

INSTITUTE OF PSYCHIATRY

De Crespigny Park
Denmark Hill
London SE5 8AF
(071 703 5411)

5.79. Director: Dr D Quinton

Children Placed Late in Permanent Substitute Family Care

This study is investigating prospectively the social and emotional recovery of 80 children aged 5–9, newly placed in permanent substitute family care, and those factors which suggest the development of a secure placement. Particular emphasis is being given to the children's earlier history, the

parenting skills of the substitute parents, and the level and kind of post-placement social work support.

The sample, drawn from one local authority in, or bordering on the Greater London area, will be stratified according to previously determined criteria which predict the rate of recovery over the first year of placement. The substitute parents will be interviewed about the children's adjustment and the parenting approaches used to deal with emotional and behavioural problems, at one month, six months and one year after placement. The children's cognitive functioning and social adjustment will be directly assessed at the first and final family contact. Social workers will be interviewed, prior to placement, about their view of the child's initial level of difficulty, and on the plans for post-placement support; then again at the one year point for their assessment of the placement, and the level of support they have provided over the year.

June 1989–June 1992 (1989/90: £10,584)

NATIONAL CHILDREN'S BUREAU

8 Wakley Street
London EC1V
(071 278 9441)

5.80. Director: Ms E Ferri

A Study of the Support and Training of Childminders

The study is the third phase of a three-stage programme of research on childminding. The aim is to examine the influence different forms of support and training have in relation to key aspects of childminding, and to evaluate what impact this has upon minders' practice.

October 1987–January 1990 (1989/90: £127,077)

UNIVERSITY OF BRISTOL

Department of Social Policy and Social Planning
Alfred Marshall Building
40 Berkeley Square
Bristol BS8 1HY
(0272 303030)

5.81. Director: Ms E Farmer

Children at Risk: Decision-Making, Intervention and Outcomes

This study explores the processes of decision-making and intervention in relation to a group of children at risk of abuse in two local authorities, and relates these to outcomes after a two-year period.

Attention is being given to the way in which risk is re-assessed over time and to the way in which decisions are made to remove, retain or restore children home.

The study is based on interviews with social workers and families, attendance at case conferences and material from case-files.

September 1988–March 1992 (1989/90: £43,639)

5.82. Director: Professor R A Parker*Monitoring of Custodianship*

Article — page 53

The custodianship provisions of the Children Act 1975, implemented in December 1985, enabled relatives, step-parents and foster parents to obtain legal custody of children in their care, while preserving links with birth parents and other family members. This research studied the use of custodianship during its first three years.

Initial investigation revealed that custodianship is used infrequently and that most applicants are relatives. During 1988, and continuing into 1989, interviews were conducted with social workers, applicants and some natural parents and older children, in cases involving 64 children in 54 families.

All the cases in progress during 1988 in four local authorities were studied, national court statistics were obtained and a postal survey was made of all social services departments in England and Wales. A small-scale postal survey enquired into the reasons why custodianship is not attractive to local authority foster parents.

January 1987–December 1989 (1989/90: £54,542)

Senate HouseBristol BS8 1TH
(0272 303030)**5.83. Director: Mr W Van Der Eyken***An Evaluation of the Sheffield Information and Referral Scheme*

This study is about parents' needs for day care, and other under-fives provision. It focuses on the extent and the range of information services for parents, within both the statutory and voluntary sectors; the extent to which these services differ in their methods of operating, and in the information they provide.

The operation of schemes like Sheffield Parents' Information Centre (PIC) is being looked at, and their local impact assessed, with a view to identifying the needs of parents of under-fives, and how best to support them. The study also aims to investigate the impact of such schemes on both existing and new provision, their influence over local policy for funding under-fives provision and the impact of such information services on individual families.

The purpose of the research is to suggest a model for an information service which could be adopted by Local Authorities — cost-effectively — to provide the best information service for parents.

April 1987–December 1990 (1989/90: £18,506)

Socio-Legal Centre for Family Studies21/22 Berkeley Square
Bristol BS8 1HP
(0272 303030)**5.84. Director: Mr M A Murch***Pathways to Adoption*

This is a study of the adoption process, taking into account changes in adoption practice since the Adoption Act 1976 came into force. The aim is to investigate and eliminate the difficulties within the process which appear to inhibit the achievement of adoption for some children — even where agencies have determined that adoption offers the best future for the child.

An initial feasibility stage involved interviews with adoption officers. The main stage has two parts: an investigation of court-based records and an investigation of adoption records in respect of the same children.

Four geographically-spread local authority areas will be covered in two stages. The extensive study looks at all children for whom freeing for adoption applications were made in 1986 and 1987 in the study areas. The intensive study looks at a sub-sample of contested and uncontested cases. The records studied are complemented by some interview and observational work.

October 1987–February 1991 (1989/90: £57,084)

5.85. Director: Mr M A Murch*Separate Representation of Parents and Children in Care Proceedings*

Article — page 46

This project examined the processes in civil courts by which children either are, or are not, represented in cases where adults lay claim to their care and custody.

Firstly, the operation of new provisions for the separate representation of parents and children in care was studied, together with proceedings in which the state, via the local authority, is one of the parties.

Secondly, the representation of children's interests in other forms of child-related proceedings, where provisions for separate representation for parents and children do *not* apply, and in which only parents or other private adults are classed as parties was investigated. The studies were then compared.

July 1984–June 1989 (1989/90: £42,226)

UNIVERSITY OF CAMBRIDGE

Child Care and Development GroupFaculty of Social and Political Sciences
Department of Paediatrics
Free School Lane
Cambridge CB2 3RF
(0223 334510)**5.86. Director: Dr M P M Richards***National Study of Triplets and Higher Order Births: The Parents Study*

Article — page 71

The National Study of Triplets and Higher Order Births was a series of linked studies analysing every triplet and higher order birth in the UK over the years 1979–80 and 1982–85. This project is a complementary *Parents Study*, undertaken by the

Child Care and Development Group (CCDG) of Cambridge University.

The objectives were to collect and analyse data on the following areas: parents' experience of medical care; current social, economic and domestic details of the household; sources of advice, help, and material benefits. The parents' survey is to be compared with complementary surveys of obstetricians, GPs and paediatricians. The researchers have also looked at the views of social services departments and community health services as to the support they could provide.

The NPEU, OPCS and CCDG have completed a book — to be published in July 1990, entitled *Three, Four and More* — which draws together all of the surveys (obstetricians, GPs, paediatricians and parents).

July 1986–March 1990 (1989/90: £14,924)

UNIVERSITY OF CAMBRIDGE

Institute of Criminology

7 West Road
Cambridge CB3 9DT
(0223 337733)

5.87. Director: Professor A E Bottoms

Evaluation of Intermediate Treatment

Article — page 58

A preliminary phase of this research, lasting 18 months, incorporated developmental work and a national survey of intermediate treatment.

Since then, the work has involved three main sub-studies, carried out with input from PSSRU (5.7, page 89): an individual outcome study, to assess the effectiveness of different kinds of intermediate treatment in reducing the criminality of juveniles; an aggregate outcome study, to test the effect of the development of intermediate treatment on the crime rates of different areas, and on their custodial sentencing rates; and a study of the administrative processes connected with intermediate treatment.

January 1984–September 1990 (1989/90: £109,720)

UNIVERSITY OF EAST ANGLIA

School of Economics and Social Studies

Norwich NR4 7TJ
(0603 56161)

5.88. Director: Ms J Thoburn

Participation in Decision-Making

The objectives of this study are to examine alternative ways of facilitating the participation of parents and older children in child protection work, and to identify the strengths and weaknesses in the different approaches to participation. It also aims to evaluate the effectiveness of different ways of facilitating participation, and to consider whether this appears to have contributed to or diminished the child's welfare.

The focus of the study is the activities of social workers, since it is they who are usually accountable for ongoing work with families and children where abuse has occurred or is suspected. The role of the Area Child Protection Committees in policy making and issues such as training is to be considered. Finally, an attempt will be made to gauge the impact of participating models of practice on the role of other professionals who are members of the child protection team.

October 1989–March 1992 (1989/90: £4,302)

UNIVERSITY OF ESSEX

Wivenhoe Park
Colchester CO4 3SQ
(0206 862286)

5.89. Director: Professor J R Butler

Child Health and Education Survey: Transfer of Data to ESRC Archives

This was a cohort study of all births in Great Britain in one week of April 1970. Information was collected at birth, age 5 and age 10, and covered medical history and measurements of the children's educational abilities, behaviour, motor coordination, blood pressure, height and weight. There was a 94 per cent contact rate at age 10 — almost 15,000 children. DH partly funded the surveys at birth and age 10.

The data-set was transferred from the Institute of Child Health, Bristol University, to the ESRC Archive at Essex University — the cost being shared between DH, DoE, the ESRC and MRC — to allow approved researchers access to data for further analysis.

January 1979–December 1989 (1989/90: £8,967)

UNIVERSITY OF GLASGOW

Departments of Child Health and Obstetrics

1 Lilybank Gardens
Glasgow G12 8RZ
(041 339 3118/9)

5.90. Director: Dr F A Boddy

Evaluative Research on Interventions in Child Abuse

This was a literature search undertaken to locate systematic studies of preventive and 'after-the-event' interventions for child abuse. Approximately 150 studies were identified and described by applying a standard classification system.

The purpose of the review was to provide an overview of the current state of this area of research, that would be of use to practitioners and researchers. Few clear answers to the relative effectiveness of different intervention methods were obtained, owing to a variety of methodological problems. The most common problems were the lack of specification of the samples and interventions in ways which were meaningful to what was being evaluated, or which allowed comparisons between studies and interventions.

August 1989–December 1989 (1989/90: £5,626)

UNIVERSITY OF LEICESTER

School of Social Work

107 Princess Road East
Leicester LE1 7LA
(0533 523776)

5.91. Director: Ms P Hardiker

Preventive Practice in Child Care Social Work

This was an exploratory study focusing on preventive practice at the secondary and tertiary level. It aimed to take stock of existing developments; to examine the feasibility of comparing preventive practice in a small number of local authorities with contrasting stated policies on prevention; and to examine how relationships between differing social work methods and practice, including related resources, and outcome could be measured.

The study had two main aspects. Firstly, a feasibility study in a small number of local authorities examined current policy, and explored how this carried through into practice. The experience of a small number of children was followed through over a period of time.

Secondly, a literature review of preventive practice in Britain and elsewhere was carried out, focusing on social work with the family and its outcome for the child.

October 1987–March 1989 (1989/90: £12,043)

UNIVERSITY OF LONDON

Institute of Child Health

Department of Child Psychiatry
30 Guilford Street
London WC1N 1EH
(071 405 9200)

5.92. Directors: Dr A Bentovim, Mrs E Monck
Contacts: Ms R Lwin, Ms E Sharland, Ms G Goodall

Sexual Abuse of Children

Article — page 40

This study comprises two parts, running concurrently, and aiming to provide systematic descriptive information on a large sample of sexually abused children and their families, and to investigate the effectiveness of group therapy as a treatment procedure.

One study is descriptive, concerning the characteristics of families at the start of the study. The second is experimental and aims to assess the outcome of treatment and the effectiveness of group therapy as a treatment method.

January 1987 — September 1990 (1989/90: £88,767)

5.93. Directors: Dr A Bentovim, Dr M Smith

Normal Sexual Knowledge in Children

Article — page 43

This is a study concerned with normal sexual knowledge in children. One aim of the study has been to collect information on the development of sexual behaviour in normal children and their families, and to assess children's sexual knowledge.

A second aim of the study is to assess, in a standardized way, how abused children differ in their behaviour and cognitions from children drawn from a normal population who have not been abused.

January 1987–March 1990 (1989/90: £25,000)

UNIVERSITY OF OXFORD

Department of Social and Administrative Studies

Barnett House
Wellington Square
Oxford OX1 2ER
(0865 270344)

5.94. Director: Mrs T Smith

Family Centres Research

This is a study to examine the activities and evaluate the impact of family centres on the neighbourhoods they serve. The study is based in six geographically-spread family centres, run by the National Children's Home. It is to be undertaken in three stages, although at this point only phase one has been commissioned.

Phase one provides descriptive information about the organization and management of centres, and about the social composition and services provision in the neighbourhoods in which the centres are based. It also examined the pattern of use of the centres by members of the local community and obtained some initial evaluative material regarding the extent to which social networks are enlarged, and social isolation reduced, amongst those who use the centres.

September 1988–March 1990 (1989/90: £12,284)

UNIVERSITY OF STIRLING

Stirling
Scotland FK9 4LA
(0786 73171)

5.95. Director: Ms C Hallett

Coordination in Child Abuse

The research aims to study the policies and practices of inter-agency coordination in child abuse. It comprises three main parts: a conceptual analysis and literature review; brief case studies of professional views of what constitutes child abuse, and the actions professionals would take in consequence; and a study of coordination policies and practices in a sample of cases of child abuse in selected areas.

The purpose of the study is to develop concepts and frameworks for analysing coordination, to study professional views and practices in order to analyse the tasks and processes involved, and to identify the structural or other factors which appear to inhibit or facilitate it.

September 1988–December 1991 (1989/90: £48,454)

Community Care

AGE CONCERN INSTITUTE OF GERONTOLOGY

King's College London

552 King's Road
London SW10 0UA
(071 872 3035)

5.96. Director: Professor A Tinker

The Provision of Segregated, Special or Integrated Social and Health Services for Elderly People from Ethnic Minorities

This is a three-part study of the provision of segregated, special or integrated health and social services for elderly people from ethnic minorities. Firstly, it assesses the scale of provision of different kinds of services to these groups; secondly, it explores the consequences of different forms of service provision — such as continuation or disbandment, client take-up, problems in implementation, consumer or staff satisfaction; and thirdly, it examines the needs and attitudes of elderly people from ethnic minorities in relation to these services.

Part one surveys all local and health authorities with significant proportions of ethnic minority elders. Postal questionnaires and telephone interviews examine types of service available, together with reasons for establishing or disbanding them, problems of implementation, and outcomes.

The second part will comprise interviews with 150 staff providing different services to ethnic minority elders to explore their perceptions, problems and preferences. For the third study, interviews are to be conducted with 250–300 middle-aged and elderly ethnic-minority people about their service knowledge, experience and preferences.

October 1989–December 1991 (1989/90: £8,562)

5.97. Director: Professor A Tinker

Resource Centres Attached to Part III Homes

A number of social services departments have started to provide resource centres attached to Part III homes for elderly people. These provide locally-based services for elderly people in their own homes and meet the current policy objectives of enabling elderly people to remain in the community, make greater use of communal facilities and involve voluntary bodies and volunteers.

The aim of the research is to find the extent to which such centres are provided and to describe the kinds of services available; to evaluate the provision from the points of view of providers, staff, elderly consumers and informal carers; and to make recommendations about future provision for elderly people.

A literature search will be followed by a postal survey of all social services departments in England and Wales. Case studies will then be carried out in six areas representing urban and rural situations. A sample of managers, staff, 150 users and 50 informal carers will be interviewed, and workshops used to disseminate the findings.

October 1989–December 1990 (1989/90: £8,455)

GOOD PRACTICES IN MENTAL HEALTH

380–384 Harrow Road
London W9 2HU
(071 289 2034)

5.98. Director: Dr J Renshaw

Evaluation of Good Practices in Mental Health

This study was commissioned to evaluate and disseminate information about a number of projects, funded by DH, and chosen at regional level as examples of good practice in mental health.

The evaluation leads directly to the dissemination of ideas about effective practice for other health authorities and local authority social services departments.

January 1987–December 1989 (1989/90: £71,935)

HEREFORD AND WORCESTER COUNTY COUNCIL

County Hall
Spetchley Road
Worcester WR5 2NP
(0905 763763)

5.99. *Worcester Development Project: Organization and Evaluation of Services for the Mentally Ill*

The Worcester Development Project was designed to develop a comprehensive local network of health and social services for the mentally ill, as outlined in *Better Services for the Mentally Ill*.

The evaluation examined local patterns of services developed in the area embraced by the Worcester and Kidderminster Health Districts.

July 1973–March 1989 (1989/90: £7,908)

INSTITUTE OF PSYCHIATRY

De Crespigny Park
Denmark Hill
London SE5 8AF
(071 703 5411)

5.100. Director: Professor I Marks

Daily Living Support versus Hospital Care: a Controlled Cost-Effectiveness Study

This research looks at evaluation and training, and is concurrent with a clinical mental illness development project. A controlled study is examining the prevention of seriously mentally ill patients, in an inner city area, from embarking on extensive in-patient care by the implementation of a daily living programme, which treats at the site of breakdown as soon as it occurs, enables patients to acquire the skills to live outside hospital, and supports helpers in the community.

Over three years, half of all local, seriously mentally ill patients, selected at random, who require first-time psychiatric

admission are being treated and maintained by the programme. The remaining half are provided with standard hospital care.

A cost–utility evaluation of the first 200 cases compares outcome of the two forms of care on clinical state, work/social adjustment, relapse rate, treatment adherence and resource utilization. An evaluative method for routine use is being evolved, while an interdisciplinary training module for care providers is also being developed within the programme.

October 1987–December 1990 (1989/90: £71,570)

5.101. Directors: Professor J Gunn, Dr D Forshaw

Development of an Integrated Computerized Management Information System for the Special Hospitals

A network of linked computers has been established to exploit the potential for information gathering, integration and processing. More sophisticated computer programmes have been developed to provide 'expert' clinical tools giving professionals of all disciplines immediate ward-based help, focusing on the initial patient assessment and then on the development and adjustment of their treatment programmes, both on a daily and a long-term basis.

The ward-based, integrated, computerized management information system will aid the development of a new service, while the computer network will be used to provide continuing evaluation of the clinical service.

The effectiveness of the computer network in performing and combining the proposed clinical, evaluative and administrative functions has been tested, and the impact on the host organization of introducing information technology has been studied.

January 1988–September 1989 (1989/90: £14,573)

5.102. Director: Dr J Brooking

Evaluation of the Work of Community Psychiatric Nurses in Primary Care

This is an investigative study into the work of Community Psychiatric Nurses (CPNs), looking at the work of 8–10 CPNs over a range of four Health Centres/Group Practices with a total list of 60,000 patients. It examines the work of CPNs with neurotic or personality-disordered patients referred directly to them as the only psychiatric professionals involved.

The study uses a randomized prospective controlled trial to investigate outcome, and a number of other methods to investigate the structure and process of the work of the CPN. The design of the study allows the investigation of several other related areas.

April 1988–March 1991 (1989/90: £46,021)

5.103. Director: Professor A Mann

An Evaluation of the Effect of Community Psychiatric Nurse Management of Depression in the Community

A population register of elderly residents has been established so that, by regular screening, incidence and prevalence morbidity data will be available. In conjunction with the

psychogeriatric team, individual management plans have been formulated for a cohort of patients screened as being depressed. The plans of half of the cohort — randomly allocated — are being implemented by the Community Psychiatric Nurses (CPNs) and the remaining half are being referred to the primary care physician for his or her usual management. The effect of CPN management is being evaluated by comparing the two groups at three months. Important factors such as physical health, social variables and so on, are also being analysed.

October 1989–September 1991 (1989/90: £9,562)

Bethlem Royal Hospital

579 Wickham Road

Shirley

Croydon CR0 3DR

(081 777 8303)

5.104. Director: Dr G Murphy

Treatment of Severe Self-Injurious Behaviour

This is an evaluation of the effectiveness of treatment for severely self-injurious people with mental handicap. Clients are being selected from a database set up in a previous DH-funded project and then matched and allocated to one of two groups — an information and assessment only control group and a behavioural treatment group. Clients are comprehensively assessed and monitored during treatment, and compared to the control group at the end of treatment and at follow-up.

September 1988–September 1991 (1989/90: £46,780)

MRC Social Psychiatry Unit

De Crespigny Park

Denmark Hill

London SE5 8AF

(071 703 5411)

5.105. Director: Professor J Leff

Evaluating the Transition from Psychiatric Hospitals to District-Based Services

North East Thames Regional Health Authority (NETHRA)'s policy of closing Claybury Hospital and partially closing Friern Hospital is to be evaluated in this study, which involves assessing the clinical and social state and quality of life of the patients involved. A set of seven schedules has been assembled for this purpose.

The research team will concentrate on long-stay, non-demented patients, 900 of whom currently reside in the two hospitals. Those who move into the districts have been matched with those who stay, and comparisons will be made one year after the initial assessment. A more comprehensive evaluation will be made of the services provided by Haringey and Islington districts.

April 1986–March 1992 (1989/90: £22,014)

LONDON HOSPITAL MEDICAL COLLEGE

Department of Clinical Epidemiology

Turner Street
London E1 2AD
(071 377 7234)

5.106. Director: Professor E Alberman

Effect of Epidemiological Changes on Future Planning and Services Strategies

This project aims to predict the incidence and age-specific prevalence of severe mental handicap due to different causes, in the birth cohorts derived from conceptions between now and the end of the century, taking into account the effects of likely changes in demography and advances in medical care.

Data are being gathered through a literature survey of publications relating to causes of severe mental handicap, known or probable risk factors, and recent developments in prenatal diagnosis, neonatal and paediatric care. A survey of researchers, to ascertain likely new developments over the period, is also being carried out.

The findings will form the basis of predictions for populations of different demography or other risk status. These predictions will then be published in a guidebook, to assist authorities in the planning of local medical and educational services over the next 30 years.

August 1989–July 1991 (1989/90: £8,412)

NORTH WESTERN REGIONAL HEALTH AUTHORITY

Central Manchester Health Authority

Manchester Royal Infirmary
Department of Psychiatry
Oxford Road
Manchester M13 3BX
(061 276 1234)

5.107. Director: Dr F Creed

A Comparison of Day and In-Patient Treatment for Acute Psychiatric Illness

The study randomly allocated to in-patient or day-patient care at least three-quarters of all patients admitted to hospital. Only those who were extremely disturbed were excluded.

Following this, two assessments were made. Firstly, those patients and illnesses most appropriately treated in the day hospital and in-patient units were identified. Secondly, the clinical and social recovery of these patients was measured at three months and one year after admission, to see whether day hospital care — where the patient is not removed from his or her home environment — would produce superior social recovery.

In order that findings could be generalized, the study was conducted both in Central Manchester — at a teaching hospital with a deprived inner city population — and in Blackburn, which serves a larger and partly rural catchment area.

August 1986–December 1989 (1989/90: £5,537)

NORTH WEST THAMES REGIONAL HEALTH AUTHORITY

Harrow Health Authority

Northwick Park Hospital
Watford Road
Harrow
Middlesex HA1 3UJ
(081 864 3232)

5.108. Director: Professor E Johnstone

Assessing the Needs of Chronic Schizophrenics Living in the Health District of Harrow and establishing a Database

It is known that there are many hundreds of chronic schizophrenic patients living in Harrow, and their number is being continually increased by resettlement programmes. As a proportion of these patients is not known to existing services, the purpose of the current study is to quantify this group of chronic, disadvantaged patients and establish a database for planning purposes. An estimation of their needs and requirements within the community is also being made.

The research team aims to be able to identify all schizophrenic patients (International Classification of Diseases (ICD) codes 295 and 297) discharged from Shenley and Northwick Park Hospitals during the period 1975–1985. Using standardized measuring and rating instruments, patients' mental state, physical health and social functioning are being assessed. This data may then be used for planning purposes.

February 1987–June 1990 (1989/90: £20,762)

NUFFIELD INSTITUTE FOR HEALTH SERVICES STUDIES

Fairbairn House
71–75 Clarendon Road
Leeds LS2 9PL
(0532 459034)

5.109. Director: Mr G Wistow

A Study of Development and Implementation on Consumer-Oriented Inter-Agency Strategy on Community Care

This project is studying the process of implementing an inter-agency, consumer-oriented strategy for community care. Basing its research on the Birmingham Community Care Special Action Project, it aims to facilitate the implementation of such a strategy in Birmingham and elsewhere, and consists of three parts.

Study One explores the different ways in which the Special Action Project promotes consumer involvement in service planning and delivery. The second part examines how this approach is introduced to and taken up by the relevant agencies throughout the city. Lastly, ways of monitoring the extent to which this objective is successful are to be developed.

The research reports will contain specific recommendations for further action within the city, and practical guidance for other authorities wishing to pursue a similar strategy.

April 1989–August 1991 (1989/90: £27,800)

OXFORD REGIONAL HEALTH AUTHORITY

Aylesbury Vale Health Authority

Buckingham Mental Health Service
22 High Street
Buckingham MK18 1NU
(0280 812925)

5.110. Director: Dr I H Falloon

Management of Schizophrenia in the Community

This was a study of the clinical and economic effectiveness of two forms of psychiatric management for patients with chronic functional psychoses (schizophrenia and affective psychoses) living in the community.

Two groups of patients were matched. One group received psychiatric care from a small psychiatric team who worked closely with GPs but without psychiatric in-patient or day-patient facilities. The other group was given a traditional psychiatric service based on hospital in-patient, out-patient and day-patient facilities.

The study patients were assessed on a number of clinical and social measures at entry, after two years, and at two-monthly periods in the interim. The contribution of the patients' GPs was assessed in relation to their personal and practice characteristics.

September 1986–October 1989 (1989/90: £10,533)

POLICY STUDIES INSTITUTE

100 Park Village East
London NW1 3SR
(071 387 2171)

5.111. Director: Ms I Allen

Services for Elderly People: Choice, Participation and Satisfaction — An Exploration of the Issues

This is a study designed to explore the ways in which elderly people actively participate in decisions about their receipt of services, with special attention to those elderly people 'at the margin' of community and residential care.

The main questions posed are the extent to which elderly people have a choice in the care services they receive from all sources, how they are helped to make choices by means of information, advice and counselling, and the extent to which they feel satisfied that these are the most appropriate services for their real needs.

The study looks at the experience of elderly people, their carers and professional advisers, and contributes to the wider debate about the issues of choice and participation.

October 1987–June 1990 (1989/90: £77,712)

SOUTH WEST THAMES REGIONAL HEALTH AUTHORITY

Wandsworth Health Authority

St George's Hospital Medical School
Cranmer Terrace
Tooting
London SW17 0RE
(081 672 9944)

5.112. Director: Dr T Burns

A Randomized Trial of Community Versus Traditional Psychiatry

All referrals to the psychiatric services of the defined catchment area have been randomly assigned to one of the two teams of consultants which share that area. The control team is operating a standard NHS service, offering out-patient assessments, Consultant Domiciliary Visits or admission as indicated, while the community team offers multidisciplinary domiciliary assessment for all patients within ten days of referral. Treatment is carried out at home where requested, involving daily visiting when necessary.

Patients are assessed by a research team at intake and at regular intervals for up to one year. Initial demographic data, clinical state, social functioning and consumer and professional satisfaction are assessed using standardized semi-structured interviews. Longitudinal data are also being collected to allow a detailed comparison of the patterns and costs of the respective consumptions of care.

Three pairs of consultants willing to have their joint catchment areas investigated in this manner have been recruited and a total sample of 150–200 patients is being studied. The design aims to ensure a representative patient sample, including chronically ill and involuntary patients.

July 1986–December 1990 (1989/90: £42,977)

TAVISTOCK INSTITUTE OF HUMAN RELATIONS

The Tavistock Centre
Belsize Lane
London NW3 5BA
(071 435 7111)

5.113. Director: Dr E Miller

Monitoring the 'Helping the Community to Care' Self-Help Alliance

As part of its *Helping the Community to Care Initiative*, the Department provided funding over a period of three years to 18 local development projects, mostly based in generalist voluntary agencies. The management of this programme was vested in the Self-Help Alliance (SHA), a temporary consortium of national voluntary organizations.

The task of the Tavistock Institute research team has been to evaluate the scheme as a whole and to promote self-evaluation at all levels. One particular innovation has been the use of research groups, each consisting of a sub-set of local development workers and research team members, to explore specific topics.

October 1985–June 1990 (1989/90: £69,042)

5.114. Director: Dr E Miller

Demonstration Districts for Informal Carers

As part of its initiative known as *Helping the Community to Care*, the Department of Health has funded three Demonstration Districts as a basis for exploring ways in which voluntary organizations can provide support to informal carers. Informal carers have been defined as people who take primary responsibility in the home for the care of a person who, owing to handicap or illness, needs almost continuous care.

The Institute has been funded to monitor the initiative, working alongside the organizations involved in it, in the task of evaluating their activities, reviewing the lessons emerging, and preparing reports on their work.

January 1986–August 1990 (1989/90: £33,474)

UNIVERSITY OF BIRMINGHAM

Department of Social Medicine

The Medical School
Edgbaston
Birmingham B15 2TJ
(021 414 3344)

5.115. Director: Professor E G Knox

North Warwickshire Mental Handicap Research Project

The aim of this study is to evaluate four residential facilities in the community, in North Warwickshire Health District, both in terms of the residents' quality of life and the costs, and to study a comparison group of residents still in hospital.

The relative merits of each care environment for the different types of client are being identified, and the relationship between staff and quality of life for the residents considered. Residents and staff have been interviewed.

June 1986–June 1990 (1989/90: £15,164)

UNIVERSITY OF BRISTOL

Norah Fry Research Centre

32 Tyndall's Park Road
Bristol BS8 1PY
(0272 238137)

5.116. Director: Dr O Russell

Physically Aggressive Behaviour by Severely Mentally Handicapped People

This is the second phase of a study of severely aggressive behaviour in people with mental handicap. The first phase examined the nature, extent and circumstances in which such behaviour occurred. This second phase evaluates in detail selected interventions identified in the first phase, and will attempt to explain their effectiveness in particular cases.

Appropriate methods of evaluating the efficacy of the interventions are being identified and tests of 'evaluability' will

be carried out. The methods of evaluating interventions and treatments are to be piloted in existing settings, including some where non-traditional, creative approaches to therapy — such as dance, music and relaxation — are used.

June 1987–August 1991 (1989/90: £38,865)

5.117. Director: Dr O Russell

Contacts: Dr C Robinson, Dr K Stalker

Respite Care for Children and Young People with Learning Difficulties

This study describes the nature and range of respite services provided for children and young people with learning difficulties by social services departments and health authorities in three different local authority areas in Somerset, Croydon and Sheffield.

Designed in two parts, the study will first establish the numbers of people using these services, those awaiting placement, and identify the social and demographic characteristics of each group. It will also establish the number of people in each area not currently in contact with such services, but who are eligible to use them.

The second stage involves semi-structured interviews with samples of parents using different types of respite service — family-based, local authority residential units, health authority provision and social-services-sponsored holidays in voluntary settings.

November 1987–June 1991 (1989/90: £75,667)

Senate House

Bristol BS8 1TH
(0272 303030)

5.118. Director: Mr W Van Der Eyken

'Helping the Community to Care' Initiative

This is an evaluation of a 'small grants' scheme within the Departmentally-funded *Under-Fives Initiative*. The aim is to examine how the scheme has operated and what has been its impact on the six national voluntary agencies through which the grants have been distributed.

Specific objectives are to answer the following questions: how and why did the agencies distribute the grants; how did the various distributions relate, if at all, to the membership of the agencies; what was the local impact of receiving a small grant and what impact did 'small grant' distribution have on the agencies themselves and on their relationships with local authorities, at both national and local level, and on the membership.

August 1988–December 1990 (1989/90: £3,639)

BRUNEL UNIVERSITY

Institute of Organizational and Social Studies

Uxbridge
Middlesex UB8 3PH
(0895 74000)

5.119. Director: Ms A Melia*'Helping the Community to Care: Home from Hospital Initiative'*

This is a three-year evaluation programme, in collaboration with DH and Age Concern (England), The British Red Cross, and the Continuing Care Project (Birmingham), selected for participation in the DH-sponsored *Helping the Community to Care: Home from Hospital Initiative*.

The aim is to improve care for elderly people, by assisting families, volunteers, neighbours and other carers to provide informal care more effectively and with greater confidence. In collaboration with statutory services, project staff will provide a coordinated system of hospital discharge and aftercare, to ensure the smooth transition of patients from hospital to home; to support patients and their carers in the immediate post-discharge period, and in some projects for additional, specified periods; and to provide volunteers with training to support them in their work; to ensure competence and instil confidence.

The research design for evaluation uses a variety of quantitative and qualitative social science methods.

June 1985–March 1990 (1989/90: £61,663)

UNIVERSITY OF HULL

Institute of Health Studies

Hull HU6 7RX
(0482 465308)

5.120. Director: Dr A M Alaszewski*Evaluation of Dr Barnardo's Intensive Support Unit in Liverpool for Profoundly Mentally-Handicapped Children*

Barnardo's Croxteth Park Project was a community-based residential unit staffed by residential social workers, designed to prepare children for placement in families. It was a radical experiment which challenged the prevailing view that children with a profound mental handicap had so many health problems that they would require long-term care in the health-service-based facility.

This study monitored the processes used by Barnardo's to establish and operate the project, and evaluated the success of Barnardo's in achieving its objectives. This included monitoring the psychological development of the children, using psychological assessment procedures, examining the quality of care, and studying the costs of the project.

The results have been widely disseminated to other agencies, and a book — *Normalisation in Practice: Residential Care for Children with a Profound Mental Handicap* — edited by A Alaszewski and Bie Nio Ong, will be published by Tavistock/Routledge in 1990.

August 1983–June 1989 (1989/90: £3,266)

UNIVERSITY OF LIVERPOOL

Department of Psychiatry

Royal Liverpool Hospital
PO Box 147
Liverpool L69 3BX
(051 709 6022)

5.121. Director: Professor J Copeland*Nursing Homes for the Elderly — Experimental Schemes for the Elderly Mentally Ill*

With support, many of the elderly mentally infirm can be cared for in the community, but many without such support at present go into institutional care. DH is encouraging the development of three district experimental schemes — in High Wycombe, Hertford and Liverpool — to provide 'homely care' of a less institutionalized nature, nearer to the families of patients.

The purpose of this research is to describe the demographic and service setting of these schemes and their functioning, as well as to evaluate the outcomes for patients and relatives. The findings will assist DH, health and local authorities in developing care for the elderly mentally ill.

October 1984–June 1990 (1989/90: £98,371)

UNIVERSITY OF LONDON

Centre for Physiotherapy Research

King's College
Strand
London WC2R 2LS
(071 836 5454)

5.122. Director: Dr C J Partridge*Centre for Research into Physiotherapy*

The centre aims firstly to initiate and carry out research related to evaluating the effectiveness of different aspects of physiotherapy practice; and secondly, to provide a focal point for the development of physiotherapy research.

One study underway is critically reviewing the effects and the effectiveness of the nine types of electrotherapy equipment commonly used by physiotherapists in the NHS.

These reviews will be used as a basis for identifying questions for future research and for setting up centres in health districts throughout Britain, which will take on responsibility for updating the reviews and providing national reference points: the Centre for Physiotherapy Research will maintain a coordinating role.

November 1980–July 1992 (1989/90: £100,594)

London School of Economics

Houghton Street
London WC2A 2AE
(071 405 7686)

5.123. Directors: Professor H Glennerster, Dr Korman*Darenth Park — A Study of Joint Service Planning*

This study has presented as complete an account as possible of the variety of activities undertaken by all the authorities involved in the closure of Darenth Park Hospital.

The account includes the strategic role played by the officers at regional level, the planning activities by the district health authorities and their corresponding local authorities in preparing services to receive residents from the Hospital, and the management of the Hospital's closure over a seven-year period.

The study also produced a costing of the new services attached to individual clients discharged from hospital, and examined the issues each hospital closure will have to face. A book has been published.

October 1981–January 1989 (1989/90: £2,170)

UNIVERSITY OF LOUGHBOROUGH

Centre for Research in Social Policy

Department of Social Sciences
Loughborough
Leicestershire LE11 3TU
(0509 263171)

5.124. Director: Professor A Webb
Contacts: Mr Doyle, Mr I Mocroft

Opportunities for Volunteering: Monitoring and Evaluation

The purpose of the research is to provide information to help the Department in its assessment of the impact and usefulness of the Opportunities for Volunteering Programme.

The research uses data from the original application forms for the scheme, from questionnaire returns provided by all recipients of funds, and includes a series of more intensive case studies carried out by interview.

Software development, in the form of a computerized Management Information System, is a major innovation of this research to date.

October 1983–March 1993 (1989/90: £132,865)

5.125. Contacts: Mr B Hardy, Mr A Turrell, Professor A Webb, Mr G Wistow

Joint Planning, Collaboration and Cost-Effectiveness

The aim of the research was to examine the nature, extent and effectiveness of joint planning arrangements and to analyse the patterns and procedures of joint allocation.

A secondary purpose was to examine the decision processes associated with the chosen schemes and the extent to which cost-effectiveness had been a consideration in their appraisal and approval. An associated project was carried out at the University of York.

September 1985–July 1989 (1989/90: £26,354)

5.126. Director: Professor A L Webb (0509 223350)

Community Mental Handicap Teams (CMHTs) — Organization and Operation

The research consists of a group of case studies, designed to complement other existing and planned work on CMHTs in England and Wales. In particular, this research

aims to extend our understanding and knowledge of CMHTs and their impact by concentrating upon teams working more closely within the philosophy and guidelines of the National Development Team.

The primary focus is, therefore, on teams whose formal objectives centre upon service delivery and service coordination. Within this context, it seeks to identify and assess team objectives and operational policies; their organizational and policy frameworks; patterns of teamwork and team outputs. Attention is concentrated particularly upon identifying variations in the interrelationships between such factors.

The findings of this research, in association with those from related projects, will provide a better understanding of professional relationships at field level, and will highlight the implications of different organizational and working methods.

September 1985–June 1990 (1989/90: £32,504)

UNIVERSITY OF MANCHESTER

Department of Nursing

Stopford Building
Oxford Road
Manchester M13 9PT
(061 275 5333 FAX 061 275 5584)

5.127. Directors: Professor C A Butterworth, Mr C Brooker

Community Psychiatric Nurses' Care of Schizophrenic Patients

The aim of this project is to develop and test a teaching programme with a group of Community Psychiatric Nurses (CPNs).

The teaching programme uses a behavioural problem-solving approach and focuses on the health education aspects of care.

Overall, the objective is to enable the CPNs to provide more appropriate care for schizophrenic patients and thus reduce the incidence of relapses in such patients.

December 1988–November 1991 (1989/90: £26,970)

Faculty of Economic and Social Studies

Department of Social Policy and Social Work
Manchester M13 9BL
(061 275 4777)

5.128. Director: Dr N Raynes

Costs and Quality of Care in Residential Settings

This is a study of alternative forms of residential care for mentally-handicapped people. The objectives are to assess and compare residential facilities on specific dimensions of care; to examine the relationship between the costs and quality of care and other factors; to assess whether these contribute to variations in costs between residences; and to assess whether organizational and staffing characteristics contribute to variations in the quality of care between residences.

The sample has been stratified by size and type of administering agency, whether health, social services, voluntary or private. Cost data are being collected by the Centre for Health Economics (5.22, page 99) from local authorities, health and voluntary sectors, following the methodology developed in a study of the costs of alternative forms of NHS for people with a mental handicap (1982–1984).

April 1987–March 1990 (1989/90: £63,054)

UNIVERSITY OF NOTTINGHAM

Child Development Research Unit

University Park
Nottingham NG7 2RD
(0602 484848)

5.129. Director: Professor E Newson

Evaluative and Comparative Study of Current Interventions for Children with Autism

This is the second phase of a study looking at current interventions explicitly provided for children perceived as autistic. Four distinct types of intervention, seen as specifically designed for autistic impairments, are being assessed: two behavioural approaches — one skill-focused and one prioritizing social relationships and dialogue skills, both verbal and non-verbal, Waldon approach and 'holding therapy'. Some children who attend Special Learning Difficulties (SLD) schools without any specialized interventional package are also included.

Data are being collected using interviews with staff and parents, video observation and repeated checklist information devised in consultation with participants. The research will produce information accessible to staff and parents in written and video form.

October 1989–October 1992 (1989/90: £46,646)

Department of Mental Handicap

Queen's Medical Centre
Nottingham NG7 2UH
(0602 421421)

5.130. Director: Dr C Cunningham

Consolidation of the Kent Down's Syndrome Cohort Study

The main aims of the study are to consolidate the data gathered on the cohort, and to establish a computerized database which would include all available information. The sources are various, for example: case notes, which contain descriptions of family difficulties and adjustment, and health problems; case cards containing child variables such as gender, developmental scores, educational history, transition to adulthood, placement, adaptive behaviour scores, and descriptions of temperament; and some computerized datasets for the follow-up study.

The study aims to clarify the benefits of intervention noted in earlier studies, and its findings will contribute to the ongoing debate on the nature of early support for families with learning-disabled children.

January 1989–June 1990 (1989/90: £10,638)

Department of Psychiatry

Floor A
South Block
Clifton Boulevard
Nottingham NG7 2UH
(0602 484848)

5.131. Director: Professor J F Cooper

Studies based on the Mapperley Psychiatric Case Registers

The Case Register is a patient-based, longitudinal, computerized information system, which contains information spanning ten years and has been made conterminous with the Nottingham Health District (population 600,000).

The main types of work undertaken during this research fell into three broad categories: the identification of defined groups of patients for both longitudinal and cross-sectional studies of their service experience; the use of the register as a sampling frame to assist in studying the administrative incidence and prevalence of psychiatric conditions, and of different types of service contact; and the monitoring and evaluation of changes in the services themselves.

October 1974–March 1989 (1989/90: £12,056)

UNIVERSITY OF SOUTHAMPTON

Centre for Evaluative and Developmental Work

Department of Social Work Studies
Highfield
Southampton SO9 5NH
(0703 592614/592565)

5.132. Director: Mr C R Lovelock

Literature Review on Blind and Partially-Sighted People

This study has been commissioned to produce a comprehensive listing of recent and current research in relation to the social care and service needs of blind and partially-sighted people, and the delivery of services to meet them. An analytical essay will give an overview and identify areas where further research is needed.

September 1989–September 1990 (1989/90: £43)

UNIVERSITY OF WALES

College of Medicine

Heath Park
Cardiff CF4 4XN
(0222 755944 x 20890)

5.133. Director: Dr S K Armitage

The Role of Hospital-Community Liaison Nurse

The role of hospital-community liaison nurse was created to improve the continuity of patient care. This project aimed to establish a baseline of data on existing schemes for hospital-community liaison nurses in Wales.

The effectiveness of these schemes was assessed with the help of participating nurses, and took account of the views of patients at home after leaving hospital.

The results will lead to further developments in the employment of hospital-community liaison nurses to help with discharge planning, and will encourage closer working relationships between hospital and community nurses.

September 1985–December 1989 (1989/90: £17,766)

Mental Handicap in Wales: Applied Research Unit

St David's Hospital
Cardiff CF1 9TZ
(0222 226188)

Director: Dr D Felce

This programme is concerned with evaluating the impact of the All-Wales Strategy (AWS) on the lives of people with mental handicap.

5.134. Service Developments

This is a follow-up of a 50 per cent sample of people with mental handicaps in four geographically distinct areas of Wales, and will identify changes in circumstances and lifestyle attributable to service development over four years of the AWS.

5.135. Studies of Day Services for Adults

Two areas of work have been commissioned: one to survey adult training centres in Wales and compare representative examples of distinct types of programme offered; and a second to develop and evaluate a supported employment service for adults with severe handicaps.

5.136. Refining Measures of Quality of Community Residences

Established measures taken from the research literature are being applied to a number of staffed community houses; a cross-validation exercise will then be undertaken to determine their relative properties. The results of this project will inform the incorporation of quality assessment into routine monitoring in a practical way.

5.137. Challenging Behaviour in the Community

This project aims to evaluate the effectiveness of new specialist support arrangements, being established in two counties, to help people with severe challenging behaviours to live in the community. The research will contribute to an understanding of the causes of challenging behaviour and means of effective intervention.

June 1975–August 1994 (1989/90 programme grant: £154,502)

UNIVERSITY OF YORK

Department of Social Policy and Social Work

Heslington
York YO1 5DD
(0904 433494)

5.138. Director: Mr J Brown

Changing Patterns of Residential Care for Mentally-Handicapped People: Implications for Nurse Training

The study aims to monitor the implementation of the syllabus introduced in 1985 to train Registered Nurses in Mental Handicap.

A cohort of students in five schools from different parts of the country have been followed throughout the training experience. Attrition rates and career moves within 6–9 months of qualification have also been collected.

January 1985–June 1990 (1989/90: £3,222)

5.139. Director: Mr J Brown

Transferability of Mental Handicap Nursing Skills from Hospital to Community

This study aims to identify the most cost-effective way in which scarce skills are used to the benefit of the consumer, and to evaluate the varying patterns of skill-mix.

Using quantitative and qualitative data, the study involves a trawl of health, social services and the voluntary independent sectors to establish a database of employment patterns. Management practices, consumer satisfaction and cost-effectiveness are to be studied in three selected areas.

Possible relevance for other groups will be indicated in final recommendations for policy.

August 1989–July 1991 (1989/90: £19,390)

Primary Health Care

INSTITUTE OF PSYCHIATRY

Addiction Research Unit

De Crespigny Park
Denmark Hill
London SE5 8AF
(071 703 5411)

5.140. Director: Mr A Glanz

The Role of GPs in the Treatment of Drug Misuse

In this study, data have been collected using a postal survey of a random sample of GPs in England and Wales, to obtain a detailed picture of the extent and nature of their involvement in the treatment of drug misusers. It also aims to identify factors which influence their response to these patients.

August 1989–July 1990 (1989/90: £8,512)

SUNDERLAND POLYTECHNIC

Pharmacy Practice Unit

School of Pharmaceutical and Chemical Sciences
 Galen Building
 Green Terrace
 Sunderland SR2 7EE
 (091 567 6231)

5.141. Director: Dr R Walker

Evaluation of Patient Medication-Compliance Aids

The aim of this study is to evaluate patients' satisfaction and acceptance of various medication-compliance devices. It involves a large-scale, multidisciplinary, comparative study of the design, practical use and psychological and social effects of compliance aids.

One thousand patients (age range 55–75 years), have been recruited to participate in the study by the Sunderland Health Authority, and randomly assigned to receive one of five compliance aids. Patients' reactions (social and psychological) to, and use of their compliance aid are being assessed at home visits.

The study is being carried out to rationalize future developments and expenditure on such aids.

September 1988–July 1990 (1989/90: £10,580)

ASTON UNIVERSITY

Pharmacy Practice Research Group

Aston Triangle
 Birmingham B4 7ET
 (021 359 3611)

5.142. Director: Mr M H Jepson

Role of the Community Pharmacist

This project has been commissioned to investigate the needs, expectations, perceptions and experiences of people using community pharmaceutical services. The needs of specific client groups (target groups) will receive particular attention and the research will result in an appraisal and recommendations.

July 1989–September 1990 (1989/90: £32,392)

UNIVERSITY OF KENT

Centre for Health Services Studies

Cornwallis Building
 Canterbury CT2 7NZ
 (0227 764000)

5.143. Director: Dr M Calnan

Re-analysis of Existing Data on Consumer Satisfaction and Health Promotion

The aim of this project is the detailed analysis of data collected from a survey carried out in Kent in the spring of 1988, which,

as part of a World Health Organization–European initiative, examined consumer views and satisfaction with the primary care service.

A questionnaire was sent to a random sample of the population aged 18 and over who lived in the Canterbury and Thanet Health District. Sixty-two percent of the 735 who were selected for study sent back a completed questionnaire.

December 1989–November 1990 (1989/90: £675)

5.144. Director: Professor J R Butler

A Follow-Up Study of the Behaviour and Attitudes of General Practitioners towards Preventive Health Care

The broad aim of this study is to establish baseline and follow-up data about the behaviour and attitudes of GPs towards health promotional services.

This is being achieved by conducting further analyses of information gathered from a national sample of GP principals carried out in 1984 and then constructing cohorts of doctors from the second survey in 1989.

April 1989–September 1990 (1989/90: £2,978)

UNIVERSITY OF LONDON

School of Pharmacy

29/39 Brunswick Square
 London WC1N 1AX
 (071 837 7651/8)

5.145. Director: Dr G Harding

The Role of the Health Centre Pharmacist

The introduction of pharmacists into health centres has a number of potential advantages, such as facilitating regular discussion with medical practitioners on prescribing patterns and information about medicines. This two-stage study examined the health centre pharmacist's role in the delivery of primary health care, and determined the extent to which these advantages had been realized.

In the first stage a questionnaire was sent to about 105 health centre pharmacy managers to collect baseline information — for example, staffing levels in the pharmacy, and opening hours. The second involved a qualitative study of the patterns of interaction between patients, the primary health care team and the pharmacist. This two-level approach was designed to clarify how the relationships between these three groups are worked out.

December 1986–December 1989 (1989/90: £41,019)

St George's Hospital Medical School

Cranmer Terrace
 Tooting
 London SW17 0RE
 (081 672 9944)

5.146. Director: Professor P Freeling

The Impact of New Technology on Investigations in General Practice

Technological advances in diagnostic equipment are likely to have a major impact on the process of care in general practice in the coming years. This investigation, undertaken in conjunction with Dr J Stilwell at Warwick University, is testing a generally applicable, systematic methodology for the appraisal of new technologies, using some of the newer tests already available to GPs.

Two bacteriological and two biochemical tests are being studied, all practices receiving each pair of tests for six months. This will be followed by a controlled trial to determine the outcome of using two of these tests in terms of patient care, cost-utility and cost-effectiveness.

July 1989–December 1991 (1989/90: £22,394)

UNIVERSITY OF MANCHESTER

Department of Nursing

Stopford Building
Oxford Road
Manchester M13 9PT
(061 275 5333)

5.147. Director: Professor C A Butterworth

Telephone Consultation Involving Community Nurses and Health Visitors

The aim of this project is to investigate the use made of telephone consultations by nurses working in the community, and their clients. Three groups of nurses are included in the study — District Nurses, Health Visitors and Community Psychiatric Nurses. Data are being collected through three surveys: a national survey of all health authorities, to establish the frequency of telephone consultations; a telephone survey of frequent users, to establish how they use the consultations; and a survey of clients who use this means of communication, to establish their views and priorities.

October 1989–September 1992 (1989/90: £2,256)

Department of Psychiatry

Withington Hospital
West Didsbury
Manchester M20 8LR
(061 445 8111)

5.148. Director: Professor D Goldberg

Interface Between Primary Care and Specialist Psychiatric Care in the Community

This project is evaluating a new community mental-illness team approach as an interface between primary care and hospital-based mental-illness services. The new teams have been made available to a set of group practices in Wythenshawe, with comparable practices acting as controls. GPs refer patients to the multidisciplinary team, who are free to offer treatment from the most appropriate member. The team has a base in the community, and also offers sessions in the group practices.

The control practices continue to receive the traditional

services — the relationship between hospital and GP being the 'doctor's letter'. Methods of cost-effectiveness analysis are being used to evaluate the benefits of the new approach in terms of the number of patient care episodes treated, the quality of care offered, the effects on the hospital-based service, and the effects on the services offered in the health centres themselves.

September 1988–August 1991 (1989/90: £51,261)

Department of Restorative Dentistry

University Dental Hospital
Higher Cambridge Street
Manchester M15 6FH
(061 275 6660)

5.149. Director: Mr F J T Burke

The Changing Pattern of Use and Difficulties Associated with the Use of Non-Sterile Gloves in the General Dental Services

This project is collecting data relating to the changing pattern of use and difficulties associated with the wearing of non-sterile gloves in the general dental services in England and Wales.

An initial questionnaire is being sent to a random sample of 2,000 general dental practitioners, to be followed by a second after two years.

The information gathered will show the degree to which current advice on glove wearing is being followed, together with reasons for its acceptance or rejection. Data will also be obtained on the frequency of glove wearing by Dental Surgery Assistants (DSAs), and the second questionnaire will provide information about changing attitudes and habits.

April 1989–December 1991 (1989/90: £1,552)

Public Health

BRITISH MARKET RESEARCH BUREAU

Saunders House

53 The Mall
Ealing
London W5 3TE
(081 567 3060)

5.150. Director: Ms J Turtle

Immunization and Vaccination

This study linked two investigations into immunization and vaccination studies. One provided a census of all designated district immunization coordinated in England, carried out by personal interview at the workplace. The second involved a postal survey of Health Visitors, Clinic Nurses and Clinical Medical Officers in a small number of districts.

The research compared the procedures used, and the attitudes and practices of health authority employees in different districts, to identify and describe the procedures most used.

November 1988–May 1989 (1989/90: £29,325)

IMPERIAL CANCER RESEARCH TECHNOLOGY

Imperial Cancer Research Fund

Sardinia House
Sardinia Street
London WC2A 3NL
(071 242 1136)

5.151. Director: Sir Richard Doll

An Investigation of the Effect of Radon in Houses

Radon in houses is the most important controllable source of radiation exposure to which members of the general public are normally, and widely, subject. Indirect epidemiological evidence from mine studies suggests that this source of radiation may be responsible for a few per cent of all UK lung cancer cases, but there are uncertainties associated with the risk to the public from a given exposure to radon derivatives.

The National Radiological Protection Board (NRPB) and the Imperial Cancer Research Fund (ICRF) are collaborating in a case-control study with related radon measurements in Devon and Cornwall, where wide variation in radon concentrations indoors is known to exist. Some 600 hospital patients, under 75 years of age, with presumptive lung cancer diagnoses are to be compared with some 1,200 patients with unrelated diagnoses. Interviews are to be followed up by radon measurements at all current and previous places of residence.

April 1988–March 1992 (1989/90: £54,855)

MEDICAL RESEARCH COUNCIL

Dunn Nutrition Unit

Downhams Lane
Milton Road
Cambridge CB4 1XJ
(0223 63356)

5.152. Director: Dr R G Whitehead

Research on Recommended Daily Amounts of Food Energy and Nutrients

The aim of this project was to measure total energy expenditure in a randomly-selected group of normal children aged between 3 and 18 years, using the double-labelled water technique. Twenty-four children participated in this research, which, by combining measurements of energy intake with energy expenditure, will allow more valid estimates of dietary recommended daily allowances to be made.

The results will have a widespread importance in determining normal standards for energy expenditure, for investigating modern inactive life style implicated in coronary heart disease, for overcoming dietary history taking, and for investigating energy expenditure and body composition.

September 1988–December 1989 (1989/90: £23,350)

5.153. Director: Dr D F Thurnham

Biochemical Studies on Diet, including Micronutrients and Vitamin Intakes in Cancers and Infections

There is much evidence to suggest that malnutrition and disease, particularly infections and cancer, are interrelated.

Superoxide and peroxide are normal products of microsomal P₄₅₀ oxidation, as well as stimulated leucocytes, so their production may be raised by the metabolism of xenobiotics or by invading micro-organisms. A variety of defence mechanisms exists in which micronutrients play important roles in preventing active oxygen metabolites from stimulating lipid peroxidation. Thus malnutrition may compromise the body's ability to defend itself.

This research tests the influence of vitamins A, C, B₂ and carotenoids on disease. Carotenoids are particularly important in view of other research work showing potential for cancer prevention and lessening of morbidity in malnourished children.

January 1988–November 1990 (1989/90: £41,102)

NORTH EAST THAMES REGIONAL HEALTH AUTHORITY

Bloomsbury Health Authority

University College
Department of Psychiatry
Middlesex Hospital
Wolfson Building
Riding House Street
London W1N 8AA
(071 380 9468)

5.154. Director: Professor A Rosser

Global Indices to Health

This project completes the development of an index of health-related quality of life. The index combines health quality of life and mortality data on a single scale of values, subsumes health status as a subset of health quality of life and subsumes earlier versions.

It provides assessments at five levels of detail appropriate for policy, planning and evaluation of services and treatments and is applicable to both physical and mental illness, with validated clarification and scale. It also provides a comprehensive range of severity from positive well-being to total incapacity, may be combined with condition-specific rating scales and incorporates utility scales for states of different duration and time of occurrence.

An integral part of the project is the application of the index at different stages of refinement in a standard cost-utility trial of community psychiatric day care.

August 1988–July 1991 (1989/90: £45,921)

PUBLIC HEALTH LABORATORY SERVICE

61 Colindale Avenue
London NW9 5DF
(081 200 6868)

5.155. Director: Dr C Miller

A Study of Measles, Mumps and Rubella Antibody Prevalence

This study used sera obtained routinely from five Public Health Laboratory Service (PHLS) laboratories. Approximately 4,000 specimens were used to establish a baseline antibody prevalence by age for Measles, Mumps and Rubella (MMR), prior to the introduction of the MMR vaccine. This surveillance concentrated on age groups 5–7 plus and 9–11 plus, showing the effects of infant and pre-school MMR vaccination.

Future policy requirements will be assisted by this work, particularly the question of whether rubella vaccination for girls aged 10–14 years should be replaced with MMR for both sexes.

July 1987–March 1989 (1989/90: £5,947)

SOUTH WESTERN REGIONAL HEALTH AUTHORITY

Bristol and Weston Health Authority

Manulife House
10 Marlborough Street
Bristol BS1 3NP
(0272 290666)

5.156. Director: Dr R E Stanwell-Smith

Meningococcal Meningitis in the Stonehouse Area

A survey of the prevalence of *N Meningitides* and *N Lactan-nica* in inhabitants of Stonehouse, Gloucestershire has been carried out, followed by a case-control study to check medical and environmental conditions associated with carriage of these organisms.

Active smoking and smoking in the household have been identified with *meningococcal* carriage. This may help to explain the meningitis rates observed in children of smoking families, in teenagers and in military recruits.

May 1988–April 1990 (1989/90: £12,397)

TAYSIDE HEALTH BOARD

Ninewells Hospital and Medical School

Cardio-vascular Epidemiology Unit
Dundee DD1 9SY
(0382 644255)

5.157. Director: Professor H Tunstall-Pedoe

Public Accounts Committee (PAC) and National Audit Office (NAO) Report on Coronary Heart Disease: Follow-up

The adequacy of information about coronary heart disease, mortality, morbidity and risk factors in England has been called into question over recent years. This project reviewed data in England, Scotland, Northern Ireland, USA, Australia and some European countries to assess variations over time, between countries and within countries. The quality of this data was also assessed.

October 1989–December 1989 (1989/90: £34,384)

UNIVERSITY OF BIRMINGHAM

Health Care Research Centre

Department of Social Medicine
PO Box 363
Birmingham B15 2TT
(021 414 6767 FAX 021 414 4036)

Director: Professor E G Knox

The Centre's main work is presently divided between the statistical and epidemiological exploitation of some very large data-sets, and the development of predictive models for use in health care planning.

5.158. Perinatally-Determined Infant Morbidity

The aims of this research are to study and classify all cases of cerebral palsy occurring in infants born in Birmingham over a 25-year period. The cases are linked with a birth register containing obstetric and neonatal details of all births, and the associations established through the linkage process are being examined.

5.159. Postnatal Maternal Health

This study is investigating the post-partum consequences of epidural anaesthesia, and has already established that back-ache is a common after-effect. Work has progressed to examining the effects of other obstetric techniques, and to identifying the differences between those epidural anaesthetics which are associated with backache and those which are not.

5.160. Screening Decision Models

The main objectives of the project are to provide a tool for predicting the effects of different screening policies in terms of outcomes, and to undertake a series of predictive exercises and alternative policy studies based upon it.

5.161. The Epidemiology of Communicable Diseases

In response to the lack of information about how to plan effective preventive programmes for communicable diseases — for example, whooping cough and AIDS, this research is using computer models to translate measures or estimates of the effectiveness of procedures (vaccinations and/or health education) to the wider population.

March 1971–July 1991 (1989/90 programme grant: £48,090)

Institute of Occupational Health

University Road West
PO Box 363
Birmingham B15 2TT
(021 414 6030 x 6022)

5.162. Director: Professor J M Harrington

Development of a Standard Procedure in Response to the Control of Substances Hazardous to Health Regulations 1989 [COSHH]

The primary requirement of COSHH is that an assessment is made of the substances employees are exposed to, looking at both the likelihood of exposure and its potential severity.

This research has formulated guidance notes and standard pro formas which systematically cover the range of chemical exposures to be considered. The forms are suitable for use by NHS personnel, including Occupational Health Nurses, Physicians, Safety Officers, and Laboratory Managers.

The guidance and pro formas were piloted by trained hygiene staff in a district of the West Midlands RHA. They were also tested by hospital occupational health personnel to confirm the suitability of the approach.

April 1989–October 1989 (1989/90: £18,314)

UNIVERSITY OF KENT

Centre for Health Services Studies

Cornwallis Building
Canterbury
Kent CT2 7NF
(0227 764000)

5.163. Director: Dr M Calnan

Coronary Heart Disease Prevention Study in General Practice

The aims of this study are to document coronary heart prevention activity in general practice, and develop a means of evaluating its effectiveness.

The study began with a review of relevant literature and progressed to pilot testing in the first two years. The final two years consist of a national GP survey, a DHA survey and analyses of the results of these.

Proposals for the evaluative element on intervention have also been developed and are being applied in the final two years.

October 1986–September 1990 (1989/90: £67,768)

UNIVERSITY OF LIVERPOOL

Liverpool Congenital Malformations Registry

Royal Liverpool (Alder Hey) Children's Hospital
Institute of Child Health
Eaton Road
Liverpool L12 2AP
(051 228 4811 x 2695)

5.164. Director: Professor F Harris

Liverpool Congenital Malformations Registry (LCMR)

The LCMR monitors a defined geographical area, covering five DHAs in the Mersey Region and totalling approximately 20,000 births per year. Cases of congenital malformations are ascertained from birth to age 16 and compared to the numbers of total births in the catchment area.

The Registry undertakes research projects based on its own databank. These currently include: rates of neural tube defects; a comparison, with the OPCS, of congenital malformation voluntary notification; and studies of congenital malformations in babies of diabetic mothers and in relation to pregnancy history. It is also a participant in the European

Registry of Congenital Abnormalities and Twins (EURO-CAT) — in particular its collaborative heart project.

May 1974–March 1991 (1989/90: £42,947)

Royal Liverpool Hospital

PO Box 147
Prescot Street
Liverpool L69 3BX
(051 709 0141)

5.165. Director: Professor L Klenerman

Diabetic Foot Study

This project reviews more than 2,000 cases of diabetes in Merseyside to assess the health status of their feet. The study aims to propose relevant preventive health programmes so that the incidence of trophic ulceration and amputations is minimized.

November 1989–October 1990 (1989/90: £4,226)

UNIVERSITY OF LONDON

Birkbeck College

16 Gower Street
London WC1E 6DP
(071 631 6222)

5.166. Director: Dr S MacGregor

Evaluation of the Centrally-Funded Initiative (CFI) on Services for Drug Misusers

The project described and analysed the service projects supported through the CFI, using individual reports produced by the projects and separate data collection. It involved four exercises: firstly, a review of the dissemination of the CFI allocations; secondly, an analysis of the awarded and rejected proposals for CFI funding; thirdly, a census of clients and CFI services; and fourthly, case studies of a number of CFI services.

September 1986–December 1989 (1989/90: £54,899)

Unit for Metabolic Medicine

4th Floor
Hunt's House
Guy's Hospital
London SE1 9RT
(01 955 5000 x 3690)

5.167. Director: Professor H Keen

Early Detection of Susceptibility to Diabetic Kidney Disease

Insulin-dependent diabetics in eight centres are screened in overnight urine collections for small, sub-clinical increases in urinary albumin excretion rates (*microalbuminuria*), to investigate if an early — and potentially reversible — predictor of the progressive loss of renal function, culminating in end-stage renal failure, can be identified and the condition thus prevented. In 1988, approximately 230 microalbuminurics had been

detected, and 64 randomized for treatment and assessments. Screening has been extended to several additional, large patient populations, and the natural histories of diabetic nephropathy (kidney disease) in study subjects is being documented.

Also in progress are studies and trials of glomerulo-protective drugs and dietary protein modification in nephropathy prevention.

February 1984–January 1992 (1989/90: £148,664)

UNIVERSITY OF MANCHESTER

North Western Regional Drug Research Unit

Prestwich Hospital
Bury New Road
Manchester M25 7BL
(061 798 0544)

5.168. Director: Dr J Strang

Assessing Drug Treatment at Satellite Clinics of a Regional Drug Dependence Unit

The increasing number of presenting drug-takers, and the broadening concept of problem drug-taking emphasize the need for services to be more broadly based and easily accessible. This research project examined a system of 'satellite clinics' — which involve both visiting specialist staff and local generic staff — and community drugs teams, to assess the impact of such a service on local agencies.

In the preliminary stages, a data collection system was established to detect any changes in the profile of patients referred. The three districts compared during the project were geographically and locationally disparate, and allowed pre-clinical measures.

In addition to collecting satisfaction measures from local agencies, information was collected on the size of the drug taking population which was not referred, but identified by the local agency.

June 1984–June 1989 (1989/90: £3,333)

Workforce

NATIONAL FOUNDATION FOR EDUCATIONAL
RESEARCH IN ENGLAND AND WALES

The Mere
Upton Park
Slough
Berkshire SL1 2DQ
(0753 74123)

5.169. Director: Dr S Hegarty

Training Needs of Specialist Social Services Staff in Visual Handicap

This was a study of the training needs and the training provided for social services staff who work with visually-

handicapped people. The staff — mobility officers and technical officers — were interviewed, together with their trainers and line managers, and their clients' views were obtained.

The research included observational information about the work of social services staff in the visual handicap field, as well as questionnaire data, and analysis of file information.

October 1985–September 1989 (1989/90: £2,205)

5.170. Director: Dr S Hegarty

Evaluation of Experimental Schemes in Basic General Nurse Education/Training

This is a three-year study to evaluate the six English National Board pilot schemes and to study six of the demonstration schemes for Project 2000, using both quantitative and qualitative data.

February 1989–August 1993 (1989/90: £60,751)

OXFORD REGIONAL HEALTH AUTHORITY

Old Road
Headington
Oxford OX3 7LF
(0865 64861)

5.171. Director: Profesor J Parkhouse

Career Preferences of British Medical Graduates

A simple questionnaire sent to pre-registration house officers yields a high response rate and gives valuable information about career preferences.

Information of this kind has been obtained on a continuing basis since 1976, with separate cohorts of qualifiers. Experience with the initial cohort showed that follow-up was feasible, yielding important information on career pathways, influences, change of intention, emigration.

The employment position, as at 1982 and 1985, of different cohorts of qualifiers from 1974 and 1977 was examined.

January 1976–December 1989 (1989/90: £38,000)

POLICY STUDIES INSTITUTE

100 Park Village East
London NW1 3SR
(071 387 2171)

5.172. Director: Ms I Allen

Survey of Part-Time Training and Career Posts in General Practice

The study has looked at factors affecting the demand among doctors for part-time training and part-time career posts in general practice. It has also examined the extent to which various factors prevent doctors from achieving part-time training or career posts.

The aim of the research was to give the Department more information on the nature of the demand, including the number of hours or sessions required and the length of time needed in part-time employment. The constraints and difficulties which might be met in organizing general practice to provide more part-time training and career posts have also been investigated.

January 1989–March 1990 (1989/90: £49,753)

UNIVERSITY OF BELFAST (QUEEN'S)

Health and Health Care Research Unit

Mulhouse Building
Grosvenor Road
Belfast BT12 6BJ
(0232 240503)

5.173. Director: Professor C Normand

Labour Turnover

This study aims to investigate the causes of staff turnover in the NHS and the influence of labour market conditions. Data are being obtained from all NHS Regions in England, with the focus on retention, recruitment, induction and training costs. Estimates are to be made of the cost of avoidable turnover within the NHS, and the likely effects of regional pay will be assessed with a view to achieving the study's major objective: the economic analysis of NHS labour markets.

June 1989–May 1991 (1989/90: £17,517)

UNIVERSITY OF LEEDS

Rheumatism/Rehabilitation Research Unit

Medical School
36 Clarendon Road
Leeds LS2 9PJ
(0532 432799)

5.174. Director: Professor M A Chamberlain

Evaluation of Communication Aids Centres

This study is evaluating Communication Aids Centres (CACs) in relation to their aims, which are: firstly, to undertake the assessment of patients for communication aids; secondly, to spread this expertise to speech therapists and other professionals — for example, occupational therapists, doctors and social workers; thirdly, to act as an information and resource centre; and finally, to evaluate existing aids and to undertake research projects on new types of aids.

Using interviews with therapists, clients, relevant health authority managers, other key personnel, and with input from the Centre for Health Economics (5.22, page 99), data have been collected from CACs on referrals and subsequent action.

February 1987–June 1990 (1989/90: £29,727)

UNIVERSITY OF LONDON

British Postgraduate Medical Foundation

33 Millman Street
London WC1N 3EJ
(071 831 6222)

5.175. Director: Mrs R Dowie

Research into Patterns of Medical Staffing

Following the 1981 *Short Report* on medical education, this is a study of the arrangements for medical staffing in districts with different staffing patterns, the findings of which will assist DH in formulating policies on hospital medical staffing.

The fieldwork covers five districts — a London teaching, a provincial teaching and three non-teaching districts in different regions — and concentrates on general medicine, paediatrics, general surgery, orthopaedics, obstetrics and gynaecology, anaesthetics, ophthalmology and mental illness. A descriptive and statistical profile for each district is being prepared.

Semi-structured interviews with the consultants and district and regional medical manpower officers are being used. Consultants are asked about clinical, managerial and professional responsibilities, teaching and research, and about the factors affecting their clinical activities. Junior doctors are interviewed using structured questionnaires covering the organization of clinical duties, opportunities for attending courses and preparing for examinations, and career aspirations. They also record diary information for one week.

January 1988–September 1990 (1989/90: £53,725)

Institute of Education

20 Bedford Way
London WC1H 0AL
(071 636 1500)

5.176. Director: Miss J Rogers

Distance Learning Materials for Qualified Nurses, Midwives and Health Visitors

This study investigated the use made by qualified nurses, midwives and health visitors of distance learning materials, as part of continuing professional education.

During the two main phases of the research, data were collected on the provision and use of distance learning materials in five district health authorities in England and Wales, using a combination of interviews, observation and questionnaire methods. Results were discussed in relation to manpower and professional issues.

January 1986–June 1989 (1989/90: £48,109)

London School of Hygiene and Tropical Medicine

Department of Public Health and Policy
Keppel Street
London WC1E 7HT
(071 636 8636 FAX 071 436 5389)

5.177. Directors: Dr N Black, Dr M McKee

Out-of-Hours Work by Junior Doctors

This study is investigating some of the issues arising from the forthcoming changes in hospital medical staffing described in the programme *Achieving a Balance*, and aims to determine the appropriateness of out-of-hours work undertaken by junior doctors. The project is being carried out in four hospitals in the North East Thames region, and is looking at the major acute specialities.

The workload of juniors is being described using routine data and *ad hoc* studies — defects in the use of such data for this purpose will be identified. Work undertaken out of hours will be examined to determine whether it could be undertaken during normal working hours, or be delegated to non-medical staff. This will be done with a series of consensus panels after a review of any relevant literature. Possible alternative medical staffing arrangements will also be explored and obstacles to implementing them will be identified.

October 1989–March 1990 (1989/90: £6,126)

Nursing Research Unit

King's College
Chelsea Campus
552 King's Road
London SW10 6UA
(071 351 2488)

Director: Dr S Redfern
Research Consultant: Professor J Hayward

NRU is responsible for a programme of research covering two broad areas: the roles and education of nurses and midwives; and the nature, quality and organization of nursing care. The projects currently commissioned form a basis for structuring future work, particularly in relation to workforce planning, the distribution of skills, the nature of quality nursing, the organization of nursing care, and quality assurance and audit.

5.178. *The Education and Training of the Midwife*

Developments in technology, increased hospitalization, early transfer home after delivery, responsibilities in family planning and greater involvement with the family as a unit have all contributed to changes in the midwife's role over the last 20 years. This study aims to analyse the role of midwives and identify their training needs.

5.179. *Comparison of Quality Assurance (QA) Instruments for Nursing*

The objectives of this project are to describe the dimensions measured by, and the similarities and differences between the selected instruments; and to assess their reliability and validity. It aims to construct a relatively accurate picture of the validity of QA instruments, which will enable managers to make informed choices in quality measurement.

5.180. *The Role of the Ward Sister in the Nursing Process*

This project aims to investigate the ward sister's role in implementing the nursing process, primarily using a case-study approach. The implementation of the nursing process in various in-patient health care specialities is also being considered in the light of different patterns of nursing care — team nursing and primary nursing, for example.

5.181. *The Role and Responsibilities of the Nurse Working in a Secure Environment*

Training does not always provide nurses with adequate skills and knowledge in the prevention and management of violent behaviour. This research is investigating the basic and post-basic training in these skills provided for nurses, and documents the views and experiences of practising nurses in this aspect of patient care.

5.182. *Nurses' Careers*

Contact: Mrs S Robinson

The project is a study of the careers of nurses and midwives, focusing on their reasons for remaining in or leaving the health services. Using questionnaire surveys and interviews, it will provide data on a subject about which little information exists — information which is urgently needed at a time of concern over recruitment and retention levels.

October 1977–August 1991 (1989/90 programme grant: £246,282)

School of Pharmacy

29–39 Brunswick Square
London WC1N 1AX
(071 837 7651)

5.183. Director: Professor P Elworthy***Development of a Model for the Register of Pharmaceutical Chemists***

The purpose of this investigation is to determine the extent to which men and women pharmacists who graduated in 1976 have worked and, by combining these results with those from earlier cohorts, to set up a manpower predictive model for the Register of Pharmaceutical Chemists.

A sample of 500 men and women pharmacists has been surveyed to collect data on their graduation and registration dates, extent of working in each year since 1976 as a fraction of full-time work, and the branch of pharmacy in which they have worked. Using data from these surveys as well as that held by the Pharmaceutical Society, a figure for the full-time equivalence of pharmacists on the Register will be calculated.

The survey work has been completed and is being written up. The predictive work is being finalized.

April 1988–September 1990 (1989/90: £9,040)

UNIVERSITY OF MANCHESTER

University Dental Hospital

Higher Cambridge Street
Manchester M15 6FH
(061 273 6805)

5.184. Director: Professor P Holloway***Trial of a System of Capitation Payments to Dentists***

Following a one-year pilot study among 50 dentists in 21 practices to test the administrative feasibility of a system of capitation, a three-year trial — designed to compare its cost and benefits, to dentists and patients, with the existing fee-per-item-of-service system — began in 1986.

Four matched pairs of areas, three in England and one in Scotland — representing rural, industrial and suburban communities — were chosen, one of each pair being assigned to capitation with the other as a control. Seventy per cent of all the dentists in these areas responded to an invitation to participate.

Under both systems, measurements were made of costs; dental health; dentist, patient and administrator satisfaction; and patterns of treatment. The control of quality and fraudulent claims under capitation were also looked at. The results of this study were published in December 1989.

January 1984–September 1989 (1989/90: £131,267)

UNIVERSITY OF OXFORD

Rivermead Rehabilitation Centre

Abingdon Road
Oxford OX1 4XD
(0865 790236)

5.185. Director: Dr P Davies

The Demands and Pressures on Speech Therapy Departments

This was an exploratory study to look at pressure on speech therapy departments via a number of secondary data sources. Information on the incidence and prevalence of speech difficulties associated with particular types of disability, and information on referrals and treatment collected by Speech Therapy Departments themselves were used.

Data were collected by observation, interview and access to records in a small number of departments, as well as by re-analyses of existing relevant data and reference to current epidemiological data.

December 1987–February 1989 (1989/90: £8,763)

5.186. Director: Dr P Davies

The Use and Value of Speech Therapy Assistants

The research is establishing how speech therapy assistants are used in speech therapy departments throughout the NHS, how they might be developed and deployed in the future, and how valuable they are in terms of providing unmet need for speech therapy and contributing to treatment outcome.

The project comprises two studies. The first involves a skill and competence study to determine what assistants do, and how they are deployed, trained and supervised in different speech therapy departments and health districts — a questionnaire and follow-up research design is being employed for this part of the project. Part two is an implementation and evaluation study in which assistants are introduced in districts and areas, and for client groups where they do not currently exist. This is to be evaluated using a randomized controlled trial, or a matched comparison study, or a before-and-after research design, depending on what is feasible in the light of the skill and competence study. Interviews with consumers, qualified speech therapists and speech therapy assistants are also to be undertaken.

Finally, the project will include an analysis of patients' performance on standardized assessments of speech and communication, as well as an analysis of 'throughput' data such as waiting-lists, patient turnover and therapist–patient contact time.

May 1989–October 1991 (1989/90: £35,283)

UNIVERSITY OF WARWICK

Health Services Research Unit

Institute for Employment Research
Coventry CV4 7AL
(0203 523523)

5.187. Director: Mr J A Stilwell

The National Health Service and the Labour Market

The project aims to develop and implement a labour market monitoring service for professional and technical staff within the NHS. For the most part, existing data sources — such as the Labour Force Survey, and ongoing research — are being used; however, the study also seeks to clarify areas suitable for special studies, for example constructing a detailed labour market model for a specific category of staff.

Three series of reports are to be produced, focusing on relevant research, key labour market indicators, and the analysis of existing data sources. Special studies will be reported separately.

April 1989–March 1992 (1989/90: £23,149)

Nursing Policy Studies Centre

Coventry CV4 7AL
(0203 523518)

5.188. Director: Dr J Robinson

The Role of Support Staff in the Ward Health-Care Team

The study focused on the nursing skill-mix, particularly the identification, costing and evaluation of the specific contributions made by nursing support workers.

Tasks or situations which require trained nursing skills, and those which apparently do not, were identified to clarify areas where different skill-mixes may be used. In each identified situation, the marginal costs and benefits of employing proportionately more, or fewer, trained or untrained staff were estimated.

January 1988–December 1989 (1989/90: £51,182)

Non-Theme

AGRICULTURE AND FOOD RESEARCH COUNCIL

Wiltshire Court
Farnsby Street
Swindon SN1 5AT
(0793 514242)

5.189. Director: Dr J Gunning

International Comparisons in Embryo Research, Foetal Tissue for Research and Treatment, and Abortion

This study was an international comparison of published and other material about the regulation of assisted fertility treatment, embryo research, abortion and the use of foetal tissue in countries comparable with the UK. Countries studied included the USA, Canada, Australia, France, Federal Republic of Germany, Spain, Italy, Holland, Belgium and the Scandinavian countries. Activity in the EC and Council of Europe was also assessed.

Commissioned to provide up-to-date and accurate information in preparation for the introduction of the Human Fertilisation and Embryology Bill (1990), the report of the study — *Human Fertilisation, Embryo Research, Fetal Tissue for Research and Treatment and Abortion: International Information*, was published by HMSO on 5 February 1990.

August 1989–December 1989 (1989/90: £20,616)

INSTITUTE OF PSYCHIATRY

De Crespigny Park
Denmark Hill
London SE5 8AF
(071 703 5411)

5.190. Director: Professor J C Gunn

Survey of Treatment and Security Needs of Special Hospital Patients

This is a two-tier survey of patients in the English Special Hospitals. In part one, a census is being conducted of all patients. A 20 per cent sample will then be interviewed and an assessment made to determine their medical, nursing and security needs. The study will make available basic information for the planning of maximum security services in the future.

June 1989–June 1991 (1989/90: £2,500)

NATIONAL CHILDREN'S BUREAU

8 Wakley Street
London EC1V 7QE
(071 212 3434)

5.191. Director: Professor R Davies

National Child Development Study (NCDS) Fifth Sweep

NCDS is a longitudinal study of growth and development, and of social and economic change, among 16,500 people born in the UK in March 1958. Data have been collected at birth and at ages 7, 11, 16 and 23.

The department is supporting a fifth round of data collection in 1991 (when the cohort is 33) to be undertaken in collaboration with other departments and research councils. Data will be collected on the cohort, their partners and their children. About a quarter of the material is concerned directly with health and health behaviour, much of the remainder with training and employment, housing, income and wealth, family formation and change.

The aim of the study is to provide, for the policy and research communities, a major database tracing lifetime continuities and discontinuities from one point in the lifecycle to the next.

September 1989–August 1994 (1989/90: £25,000)

UNIVERSITY OF CAMBRIDGE

Institute of Criminology

7 West Road
Cambridge CB3 9DT
(0223 337733)

5.192. Director: Dr A Grounds

Anglo-French Study of Mentally-Disordered Offenders in Secure Psychiatric Hospitals

The objective of the study was to compare demographic and clinical characteristics of patients admitted to secure hospitals in England and France. Information was collected on all male patients admitted to the four English special Hospitals and the four French *Unités pour Malades Difficiles* during 1988.

April 1989–June 1990 (1989/90: £6,196)

C. Research Training Awards

The Department of Health provides funds, through the HPSS research programme, to support three award schemes to assist health care professionals allied to medicine to develop an expertise in research.

The three schemes supported during the year, and the funding set aside for them, were:

- Fellowships for the remedial professions of physiotherapy and occupational therapy (£44,959)
- Research Studentships for graduate nurses (£75,839)
- a Post-Doctoral Fellowship for nurses (£56,138)

The objective of each award is education and training in research, and the projects carried out by the students and fellows do not necessarily reflect Departmental priorities, but students' own interests. The Post-Doctoral Fellowship is the exception and, although not a commissioned study, it must relate to one of the Department's research priorities.

Those awarded and supported in 1989/90 were:

5.193. Research Fellowships for the Remedial Professions:

- Bristol Polytechnic: *Mrs L A Melarickas*
- Liverpool Institute of Higher Education: *Ms M Waldron*
- University of Birmingham: *Mrs C A Carrington*

- University of Keele: *Mrs C L Lloyd*
- University of Sheffield: *Miss M C Goode*

5.194. Nursing Research Studentships:

- Dorset Institute of Higher Education: *Ms J M Walker*
- University of Lancaster: *Miss E J Hanson*
- University of Liverpool: *Ms A Pearcy*
- University of Manchester: *Mrs K Waters; Mrs S Wilkinson*
- University of Newcastle: *Mrs L H Thomas*
- University of Southampton: *Mr A Emerson; Ms N M Morgan*
- University of Surrey: *Ms K A Getliffe*
- University of Sussex: *Ms M Freeman*

Post-Doctoral Nursing Fellowships:

- 5.195. Open University
Dr M Gott
The Health Promotion Potential of Nursing in Realizing Health for all Lifestyle Targets

D. Special Medical Developments

The Department of Health allocates centrally a small proportion of the revenue and capital resources of the Hospital and Community Health Services (HCHS) to fund projects — such as Special Medical Developments (SMDs) — where central intervention is desirable and cost-effective.

SMDs are specialized new activities, in most cases arising from research, which need to be tried — under central supervision — in several places before being commended for wider use.

The developments supported in 1989/90 were:

Project	Funding	
	Capital	Revenue (Non-Recurrent)
5.196. Care of the Elderly with Psychiatric Disorders	—	£639,000
5.197. New Genetic Techniques	£20,000	£115,000
5.198. Diabetic Retinopathy	—	£22,000
5.199. Lasers	£110,000	£240,000
TOTAL	£130,000	£1,016,000

NHS Information Technology Research

The management of the centrally-funded Information Technology (IT) projects within the NHS is the responsibility of the Information Management Group (IMG) — a joint DH-NHS body incorporating the Department of Health's NHS Information Systems Directorate (ISD) and the NHS Information Management Centre (IMC) — which reports to the NHS Management Executive's Director of Information Systems. The Research and Development (R&D) strategy is designed to complement and underpin the *National Strategic Framework for Information Technology in the Hospital and Community Health Services (HCHS)*¹, issued by the NHS Management Board in October 1986. It does this by continuing to demonstrate to the NHS the potential and acceptability of IT, to make the best use of technology, and to achieve value for money.

Following a review of the strategy, in July 1987 the IMG published a document entitled *A New Approach to Information Technology Research and Development in the HCHS*². In addition to the areas of particular strategic interest — communications and networking standards, methodologies, information requirements, planning and enabling technologies, and the development of a Common Basic Specification — the document identified the following as priority areas:

- management and clinical support systems;
- clinical information systems;
- integration of hospital systems with community systems and eventually primary care systems;
- screening systems — for example cancer, hypertension, obesity;
- diagnostic services;
- provision of portable medical records, eg Smart cards, laser cards.

The priorities set out in *A New Approach* are being kept under review in the light of recent Government initiatives.

NHS INFORMATION SYSTEMS DIRECTORATE

Projects

The need to implement the recommendations of the various Körner reports, as well as changes in management approach and, more recently, publication of the White Papers *Working for Patients* (Cmnd. 555) and *Caring for People* (Cmnd. 849), has led the Department of Health and many health authorities to undertake a

complete reappraisal of their information systems. This has created a need for more R&D across a wider spectrum.

Projects are classified into three main groups: scientific and clinical (including medical and nursing), general, and Family Practitioner Services (FPS), but care is taken to ensure that each group reinforces the other, to avoid, for example, overlooking the implications for resource management of proposed improvements in clinical methods. Proposals which would lead to better integration of patient care in hospital and the community are also sought.

Whether or not an individual project receives support depends on the extent to which the system to be developed:

- appears to meet a recognized need, felt throughout the Health Service, as opposed to a local need;
- is suitable for easy transfer and maintenance; and
- recognizes the contributions that industry and other agencies could make.

Scientific and Clinical Projects

Scientific and clinical projects are usually either research projects or technical studies. Research projects must involve the use of innovative computing techniques; technical studies examine, in a practical environment, the problems of applying new technologies which are likely to feature widely in clinical systems of the future.

The main scientific and clinical work is still the evaluation of a surgical modelling system at University College and Middlesex School of Medicine (project 6.2, page 140). Previous research has developed a computer graphics system which displays three-dimensional (3D) images of the skull, and models the outcome of orthodontic surgery; while a recently-completed project assesses both the practicality of using the system for regular clinical work, and the improvement in treatment it provides.

Another important project at the University College and Middlesex School of Medicine aimed to assist doctors in the diagnosis and management of female patients with lumps in the breast (project 6.3, page 141). Involving a one-year study to investigate the feasibility of implementing an advisory system for the management of the Bloomsbury Breast Clinic, the project was completed on 31 August 1989, and a report is available³.

Family Practitioner Services

Major initiatives to advance the use of computers in the Family Practitioner Services are evolving. Family Practitioner Committees (FPCs) have their registers on computer, and now operate cervical cytology and breast cancer call and recall systems for district health authorities. While software development continues in these areas, other FPC-related applications are being designed, including a heart-screening call and recall system.

Further initiatives include pilot trials to test the feasibility of electronic links between practitioners and the various FPS central bodies. Trials to test electronic links between pharmacists and the Prescription Pricing Authority (PPA), between dentists and the Dental Practice Board (DPB) (project 6.8, page 142), and between GPs and the FPCs have all been completed. National implementation of links between dentists and the DPB, using the FPS Data Communications Network, is under way, but further work is necessary to establish fully the feasibility of pharmacy-PPA links and GP-FPC links.

A research project examining the interface between GPs and GPs' computer systems — directed by ISD — is being conducted at Manchester University (project 6.7, page 142). It aims to find the most suitable and unobtrusive means of inputting and retrieving information about a patient, whilst he or she is in consultation with the doctor.

NHS INFORMATION MANAGEMENT CENTRE

The objectives of the IMC programme are to identify, develop and promote those aspects of information systems and technology management which are required by health service organizations to define, obtain and support their information and IT services. There are three major programmes: the Common Basic Specification (CBS), the Programme for Enabling Technologies Assessment and Application (PETA) and the Central *Open Systems Interconnection* Team (COSIT). Smaller programmes include data protection and information systems security, other IT standards and support for consortia of health authorities.

In March 1989, the IMC Management Board directed work towards fulfilling tasks resulting from the White Paper *Working for Patients*. All of IMC's work programmes, while following the same basic direction, have changed their emphasis to that of addressing White Paper issues, to help health authorities prepare for the management changes which must be in place by April 1991.

The major programmes are meeting these needs:

- CBS — contract management, capital charging, population needs analysis by purchasing authorities at district level.
- PETA — contract monitoring.
- COSIT — IT strategy following the White Paper shows a need for data communications and networking: the COSIT work on communications

standards and strategies has been brought into sharper focus.

Future priorities will be developed in detail as requirements for post-April 1991 become clearer.

The CBS is made up of models of data, activities and events and is independent of hardware, software and the organization's structure. Primarily, it is assisting in the development of information systems essential for the delivery of health care — automation will help the NHS to alleviate the increasing shortage of skilled staff in this area. It also helps to maintain consistency of information across the whole Service, and means that information can be used in various ways, to suit local circumstances and pursue local objectives.

The CBS programme (see 6.10, page 142), which started in 1986, comprises many individual projects. Priorities within it have been revised so that maximum support is given to the Hospital Information Support Systems (HISS) necessary for implementing the NHS reforms.

Projects completed during 1989/90:

- Minimum data-set model
- Estates
- Pathology and Pathology rule-base
- Community Operational Support System
- Human Resources management
- Ward costing
- Resource allocation service planning
- Population register
- Medical audit
- Hospital Information Support Systems

Ongoing projects:

- Pharmacy
- Care planning
- Renal, paediatric, diabetic
- Clinical process
- Maternity
- Financial management information

New projects starting in 1990/91:

- Occupation codes
- Contract management
- Public health
- Procurement methodology

Ways of using Structured Systems And Design Methodology (SSADM) and other methods for systems development and acquisition in health authorities, together with tools for automating the process, are also being investigated in the CBS work programmes.

The PETA (recently renamed the Management Focus Group) programme has been established to identify, assess and apply *enabling technologies*. This includes investigating the effective use of technology to increase productivity in the development of information systems, as well as assessing the effectiveness of management. The work is geared towards determining those aspects and products most likely to be

of widest benefit to health authorities. PETA (see 6.12, page 143) is currently undertaking work in the following areas:

- Development of management support systems for general managers at national, regional, district, acute and community unit levels: the first module will be for contract monitoring.
- *Ad hoc* strategic assessment to promote the use of productivity tools for information systems planning, development and application.
- investigation of *Computer-Assisted Software Engineering* (CASE) tools for the development of the CBS.
- investigation of the use of *Information Systems Applications Generators*, together with **relational database** technology, to produce the next generation of operational support systems, based on the CBS.

Communications standards

The NHS Central *Open Systems Interconnection* (OSI) Team (COSIT) (see 6.11, page 142) provides central support, to health authorities, in migrating their existing computer networks to an OSI environment, and in developing new, OSI-based communications frameworks. This is particularly important in view of the White Paper, as well as the European Community Decision (87/95/EEC), which requires the specification of European and international standards — especially OSI — in any procurement over 100,000 ECUs (approximately £70,000). COSIT's work in facilitating the introduction of international networking standards into the Health Service is still divided into three main projects:

OSI Demonstrator Project

The OSI Demonstrator project in Northampton Health Authority, partially-funded by the DTI, is now over half-way through the implementation phase. The main network, which connects all the computers in the Demonstrator (see figure 6.1 opposite), is in place and Message Handling Systems (based on the CCITT X.400 Recommendations) have been installed on all computers, allowing interpersonal mail to be exchanged. A series of public demonstrations and seminars is currently taking place.

POSINET

The *Prototype OSI NETwork* (POSINET) is an in-house Research and Development facility which is used to evaluate, test and gain practical experience of using new OSI products. It also serves as an NHS Reference Site for OSI products and supports various health authority projects.

POSINET has a number of OSI products available for NHS personnel's use. These include X.400 messaging, File Transfer, Access and Management (FTAM) and International Organization for Standardization (ISO) Development Environment — ISODE.

The OSI Demonstrator Project is using POSINET facilities to support software development and to test acceptance before equipment is put into operation. POSINET has also carried out capability testing, supporting the procurement of OSI products, for the two HISS sites — Darlington and Greenwich.

Currently, POSINET is developing comprehensive testing facilities for OSI products in operational environments. Starting in Autumn 1990, it plans to offer a phased testing service.

Information and Consultancy Services

These services provide the NHS with information on all aspects of OSI, including a continually updated library of OSI standards, the set of *Comité Consultatif International Télégraphique et Téléphonique* (CCITT)'s 1988 X-series Recommendations (standards) on digital data transmission, and an on-line database of OSI standards abstracts. Consultancy studies have been carried out to examine Local Area Network (LAN) standards, and a study of the use of *Abstract Syntax Notation One* (ASN.1) encoding techniques for medical data interchange is under way. More than ten consultants' reports and twenty technical notes are available to the Service, and training courses on OSI in the NHS have been developed in conjunction with an external consultancy — these are being held on a monthly basis.

COSIT has continued to liaise with external bodies, including the Central Computing and Telecommunications Agency (CCTA), British Standards Institute (BSI) and the DTI. Due to the international nature of standards, there is increasing liaison with European bodies, especially the European Workshop on Open Systems (EWOS) and the European standards bodies — *Comité Européen de Normalisation/Comité Européen de Normalisation Electrotechnique* (CEN/CENELEC).

Other programmes

Other IT standards

The objective of this work is to identify relevant IT standards (other than those within OSI) and to promote and support their use by NHS information systems users.

Consortia

Consortia of health authorities, among others, which use common information systems, are being helped to establish collaborative arrangements for directing and funding these systems.

All of these programmes and every project they contain are managed and quality-assured under project methodology procedures.

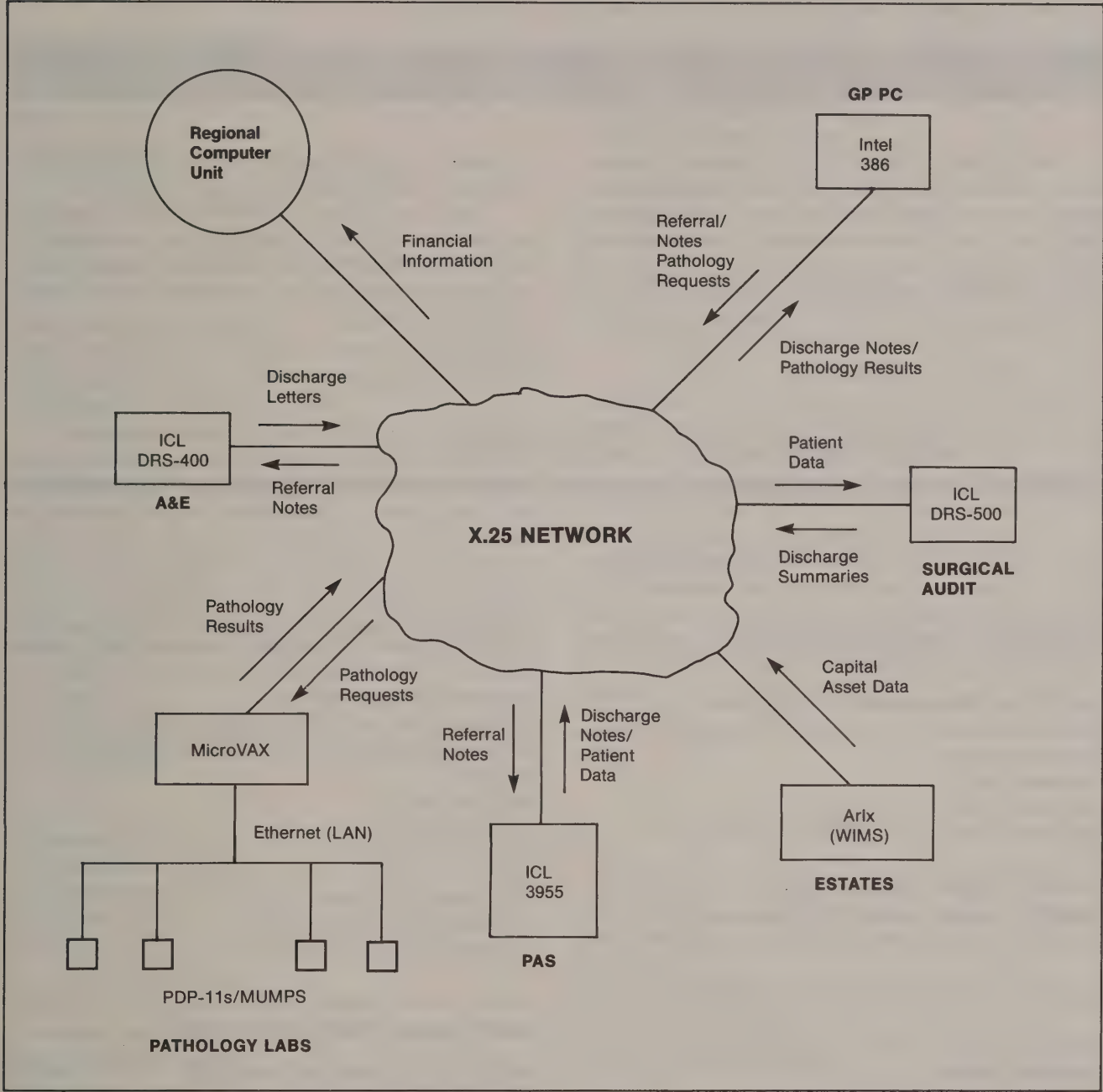
General enquiries should be directed to Barbara Micklethwaite at the NHS Information Management Centre, telephone (Birmingham) 021 454 1112. For queries concerning COSIT, please contact Mr Evans on the COSIT hotline: 021 456 2953.

References

- ¹ This publication is available from DH, Room 623, Hannibal House, Elephant and Castle, London SE1 6TE.

² Available from DH, Room 802, Market Towers, 1 Nine Elms Lane, London SW8 5NQ.
- ³ The Report of the Feasibility Study is available from DH, Room 1206, Market Towers, 1 Nine Elms Lane, London SW8 5NQ.

Figure 6.1: OSI Demonstrator: Data Flows in the Main Network



NHS Information Technology Research: Listings of Commissioned Research

The listings are in two sections. Section 1 shows research commissioned by the NHS Information Systems Directorate (ISD), and the entries are divided into three parts. Part A lists scientific and clinical projects, including medical and nursing; Part B lists general information technology projects; and Part C, work carried out for the Family Practitioner Services.

Research commissioned by the NHS Information Management Centre (IMC) is listed in section 2.

The dates shown relate to the total period of support; the figures in brackets show the amount of DH funding for 1989/90. Words and phrases highlighted in *bold italics* are explained in the *Guide to Terms*, on page ix.

1. NHS Information Systems Directorate

A. Scientific and Clinical Projects

MERSEY REGIONAL HEALTH AUTHORITY

South Sefton (Merseyside) Health Authority

District Headquarters
Fazakerley Hospital
Longmoor Lane
Liverpool L9 7AL
(051 525 3622 FAX 051 525 6086)

District General Manager: Mr D T Wood
District Commercial Manager: Mr I F Kavanagh
System Evaluator: Mr J Robert Garber (0742 333288)

6.1. Director: Mrs J Wiseman (0253 730743 FAX 0253 794403)

Development of Hand-Held Computer for Data Capture in Community Nursing

This project uses the Wiseman System (developed for DH by Mrs J Wiseman), which is based on the Husky Hand-held computer, and allows the District Nurse to increase professional nursing time whilst reducing routine statistics collection time. The computer is used with a memory card which the patient keeps at home: the nursing record and care plan contained on the card are updated by the nurse during the visit and then transferred to a microcomputer at the clinic. The health authority has started negotiations to commercialize the system.

1984 – March 1990 (Revenue 1989/90: £32,500)

NORTH EAST THAMES REGIONAL HEALTH AUTHORITY

Bloomsbury Health Authority

University College and Middlesex School of Medicine
Department of Medical Physics and Bio-Engineering
First Floor
Shropshire House
11–20 Capper Street
London WC1E 6JA

6.2. Directors: Professor J S Clifton (071 380 9700)
Professor J P Moss (071 380 9960)
Dr A Linney (071 380 9700)

System for the Simulation and Planning of Facial Reconstructive Surgery using Computer Graphics

Patients with a craniofacial abnormality are laser-scanned before and after surgery, and a set of **Computerized Tomography** (CT) scans is taken before surgery, to provide 3D information on the internal anatomy. Surgery is planned and predicted by simulation, using 3D computer graphics. Surgical outcome is predicted by referring to the initial laser-scan data and the CT data-set, together with available data on the relationships between soft tissue and bone movement. Using the measurements collected, a database is being established to increase the validity of predictions.

The laser-scan is repeated after surgery and the results are compared with the initial prediction of outcome: the complete surgical procedure is therefore described in both qualitative (image) and quantitative (data) terms.

A mathematical method of describing the surgical outcome is being developed by applying differential geometry (the study of geometrical figures using calculus methods) to the data extracted from the initial scan. This research will lead to a new method of representing the shape of the face in three dimensions.

June 1987–March 1990 (Revenue 1989/90: £63,500)

Bloomsbury Health Authority

University College and Middlesex School of Medicine
Department of Surgery
Mortimer Street
London W1N 8AA
(071 387 6145/6)

6.3. Director: Professor R R P Jackson

Advisory System for Management of the Bloomsbury Breast Clinic

This project was a one-year study into the feasibility of implementing a system to assist doctors in the diagnosis, clinical investigation and therapeutic management of female patients presenting to the Clinic.

A prototype system has been developed and an experimental version has been installed in the clinic. The prototype has two major components: a clinical **relational database** which records details of the patient's condition at each visit, together with the doctor's provisional diagnosis; and a rule-set-based **expert system**, which comes to its own diagnostic conclusions and recommends clinical management paths, based on the Clinic's agreed protocols. The expert-adviser draws on the contents of the clinical database to form its conclusions, and the database keeps a record of its recommendations.

September 1988–August 1989 (Capital 1989/90: £12,500; Revenue: £28,500)

Bloomsbury Health Authority

Computer Services Department
25 Grafton Way
London WC1E 6DB
(071 380 9509 FAX 071 380 9728)

6.4. Director: Ms C Johnston

Development and Implementation of the Bloomsbury Clinical Nursing Computer Project

The *Kardex*® and the *Care Plan* are legal documents with which nurses record patients' administrative details, health problems, interventions required and an evaluation of outcomes. This project is designed to computerize both the *Kardex*® and the *Care Plan*. It has been funded by DH and Bloomsbury Health Authority as a pilot project, to be fully implemented at the Elizabeth Garrett Anderson Hospital and the Royal National Throat, Nose and Ear Hospital during 1990.

Computerization of these systems will enable nurses to record nursing care more rapidly, accurately and concisely; enhance continuity of care — both hospital and aftercare; avoid repetition of data; and make use of information available

on other District computer systems — such as the *Patient Master Index*. It will also create a significant educational resource and establish a database of nursing practice, providing a scientific basis for planning care.

March 1984–March 1991 (Capital 1989/90: £12,000; Revenue: £29,000)

SOUTH EAST THAMES REGIONAL HEALTH AUTHORITY

West Lambeth Health Authority

Nightingale School of Nursing
St Thomas's Hospital
Lambeth Palace Road
London SE1 7EH
(071 928 9292)

6.5. Director: Ms S E Norman (DH — 071 972 2000 x 22177)

The Nightingale Computer-Assisted Learning Project

The Nightingale Computer-Assisted Learning (CAL) Project, jointly funded by DH and the Special Trustees of St Thomas's Hospital, was set up in October 1982 to investigate the development and use of CAL in nurse education.

In collaboration with the University of Surrey's CAL Group, the project team has produced a multi-purpose teaching and learning CAL package on the safe administration of intravenous drugs.

A systematic evaluation of users' perceptions of the package, and the computer as a learning medium, has been conducted in three different hospital settings. Results indicate that CAL has been well received, and clarify areas of potential difficulty.

1982–1989 (Revenue 1989/90: £2,500)

B. General Projects

EAST ANGLIAN REGIONAL HEALTH AUTHORITY

Union Lane
Chesterton
Cambridge CB4 1RF
(0223 61212 x 350 or 0223 312225 FAX 0223 53209)

6.6. Contact: Mrs J Reardon

Development and Maintenance of the National Health Service Computer Applications Register

The National Health Service Register of Computer Applications is designed to provide NHS management, computer staff and health care professionals with a comprehensive listing of computer software packages relevant to the NHS.

The Register has two functions. Firstly, it saves time by enabling an NHS department to track down a suitable application in minutes, rather than days or weeks. Secondly, it conserves NHS resources by enabling users to locate and take advantage of existing applications packages, rather than commissioning expensive customized software.

Covering three categories of software — software custom-written by or for the NHS, specialist commercial software aimed at health care applications, and general commercial software in use at one or more NHS sites — the On-Line Register provides users with instant access to a completely up-to-date version of the database. This is stored on a central computer system, and anyone with a personal computer and modem can access it through the British Telecom **electronic mail** service — Telecom Gold. 1982–ongoing (Revenue 1989/90: £70,000)

C. Family Practitioner Services

DEPARTMENT OF HEALTH

Market Towers

1 Nine Elms Lane
London SW8 5NQ
(071 720 2188 x 3717)

6.7. Director: Mr G Shipley

Improved User Interface for GPs

The project's objectives are to develop and evaluate a demonstration data-entry workstation for use in GPs' consulting rooms. Involving GPs in all phases of the design process, a flexible system has been developed and used to test alternative styles of data entry and presentation.

When demonstrated publicly, the prototype workstation received a very favourable response and commercial suppliers of GP computer systems expressed interest. The new methods tested will be incorporated in future designs and further work on the prototype will be carried out during 1990. January 1988–December 1990 (Revenue 1989/90: £50,000)

Dental Practice Board

Eastbourne
Sussex BN20 8AD
(0323 641 133 FAX 0323 39026)

6.8. Contact: Mr R Nicholson

Dentist–Dental Practice Board Electronic Links Trials

The volume of claims received by the Dental Practice Board (DPB), using existing clerical means, is more than 140,000 a

day. This project was set up to evaluate the effectiveness of using Electronic Data Interchange (EDI) to enable general dental practitioners to send claims data from their computers to the DPB, and have them validated on arrival.

Trials involved twenty-five dental practices and four dental computer system suppliers. A multi-processor (Minstrel 4®) host-system was installed at the DPB and accessed by the dental practitioner via an X.25 **Packet Switching** Data Network.

An independent evaluation of the trial, by Touche Ross Management Consultants, recommended proceeding with national implementation.

April 1988–June 1989 (Capital 1989/90: £6,000; Revenue (including evaluation): £201,000)

SOUTH WESTERN REGIONAL HEALTH AUTHORITY

King Square House
26/7 King Square
Bristol BS2 8EF
(0272 423271/428371)

6.9. Director: C Robb (DH — 071 720 2188 x 3535)

Trial of General Practitioner/Pharmacy/Dentist/Hospital Links using a Smart Card holding details of Patient Medical Records

This major project, based in Exmouth, is designed to evaluate the use of smart and memory card technology in patient-held medical records.

The project examines the potential for an integrated NHS data-handling system, using patient-held computer-readable medical records. During the evaluation, views — including acceptability and the expected benefits of such a system — have been sought from patients and the health care professionals involved.

Some 8,500 patients, from two general medical practices in Exmouth, were asked to participate in the trial. One practice aimed to involve all of its patients, while in the other, only high-volume users of the health services participated — the under-5s, over-65s and diabetics.

March 1990–October 1990 (Revenue 1989/90: £9,000; Consultancy: £12,000)

2. NHS Information Management Centre

WEST MIDLANDS REGIONAL HEALTH AUTHORITY

NHS Information Management Centre

19 Calthorpe Road
Birmingham B15 1RP
(021 454 1112 FAX 021 455 9340)

6.10. Director: Mr B W H Molteno

Common Basic Specification (CBS)

This project involves the development of the CBS — a continually evolving, conceptual model of health care delivery.

1986–ongoing (1989/90: £2,000,000)

6.11. Director: Mr P J Bishop

Open Systems Interconnection (OSI)

This is a programme providing central support to health authorities, both in developing communications strategies for transferring their existing computer networks to an OSI context, and in establishing new OSI-based communications frameworks.

1986–ongoing (1989/90: £300,000)

6.12. Director: Mr P J Bishop

Enabling Technologies

A programme to identify, assess and apply enabling technologies, including development of management support systems for general managers at all levels.

1987—ongoing (1989/90: £600,000)

6.13. Director: Mr P J Bishop

Data Protection and Computer Security

Users' data protection and computer security needs are being defined in this project. The information gained will help to produce policies and guidelines.

1986—ongoing (1989/90: £10,000)

Procurement Directorate Research

R&D OF EQUIPMENT, APPLIANCES AND SUPPLIES FOR THE NHS

The world-wide drive for new and improved medical equipment, and the pace of technological change, stimulate innovative ideas for applying newly-acquired knowledge in ways designed to help the patient or the clinician. Equipment which provides clinicians with non-invasive diagnostic aids – such as *magnetic resonance* whole body imagers – or faster, more accurate, more comprehensive laboratory tests and instruments are, potentially, very beneficial to patient care and the way in which it is provided, in reducing the costs of providing health services, and to the equipment manufacturing industry. The Procurement Directorate's programme therefore aims:

- To develop equipment for which there is a known need and where either none is available, or existing equipment fails to meet the need adequately. This may include developing essentially new equipment, if it can be demonstrated that a successful outcome will result in substantial improvements in treatment or diagnosis.
- To assist, as necessary, in improving the performance and reliability of available equipment manufactured in the UK, and, where appropriate, to stimulate British industry, particularly in the production of medical equipment with export potential.
- To provide support for its own activities, including investigating defects and establishing standards.

Project proposals are referred to independent experts for opinions on their merits.

Most of the work involved in developing new medical equipment is carried out by industry itself, which provides the finance and facilities to develop those new products necessary for its survival in the competitive world. The Department of Health plays an important role in helping UK industry to do this, through joint-venture agreements. These benefit from both the sharing of costs, and the active participation of the Procurement Directorate's technical staff in terms of project direction. Joint-venture projects with industry are, wherever possible, being channelled into LINK collaborative research programmes, which involve funding from several government bodies.

The success of the programme is particularly dependent on its ability to assist and encourage the

progression of ideas submitted by universities, health authority establishments and other research institutions, through the investment of research funds, and in the expectation that subsequent applications are resourced by private industry.

Procurement Directorate's total budget for equipment assessment and development in 1989/90 was £4.6m. Approximately £2.7m. of this was required to support the ongoing programme of equipment evaluation, which provides purchasing advice for the NHS. The remainder was committed to major research units, such as the Bio-Engineering Centre and the Orthotics Research and Locomotor Assessment Unit.

Approximately £1.9m. was provided for research and development across the board. R&D monies were allocated as shown in the table below:

	Percentage of expenditure	No. of projects underway
Medical Imaging except MR	1	2
Magnetic Resonance	24	8
Electro-medical	7	6
Materials and implants	4	5
Dental	2	3
Drugs and pharmaceutical technology	8	9
Equipment for the disabled and the elderly	49	15
Pathology laboratory	4	3
Not classified	1	3

During the financial year 1989/90, the following R&D project proposals were approved, at an estimated cost of £589,000:

- development of a computer adviser for *magnetic resonance imaging* of the head;
- development of standard layered tissue models for assessing, *in situ*, acoustic levels in ultrasonic diagnosis;
- the quantification of dynamic processes measured by *magnetic resonance imaging*;
- digital enhancement and quantitative evaluation of photostimulable-phosphor computed mammo-graphy;
- development of a monitoring and control system for ethylene oxide;
- evaluation and assessment of mycobactericidal activity;

- relative microbiological efficiencies of cobalt 60 gamma rays and accelerated electrons;
- development of an adjustable standing-frame;
- echo planar imaging and spectroscopy at 3.0T.

The outcome of the projects is monitored, and some examples of R&D successes in recent years are outlined below:

CT scanner

Without DH support, the development of a prime example of modern technological success in medical diagnostic imaging would have been severely restricted.

Magnetic Resonance

Supplies Technology Division has funded this development since its inception, and is providing support for further innovation, including systems for spectroscopy.

Anaerobic incubator

The incubator is used for isolating and testing organisms such as tetanus and gas gangrene.

Rapid Form

A machine for vacuum-forming the plastic sockets necessary for attaching artificial limbs.

Hip Guidance Orthosis (HGO)

A system of spinal and lower limb braces which enables paraplegic patients to stand and walk with the aid of crutches.

Incontinence devices for women and girls

New and more effective devices were developed.

Modular seating system

Adjustable seating support for physically-disabled people, which takes account of growth.

X-ray

Leeds Test Objects for testing the performance of radiological TV/image-intensifier systems.

Medical lasers

Development and assessment of lasers for medical use — for example, carbon dioxide and copper vapour.

General enquiries should, in the first instance, be directed to the Supplies Technology Division (STD) of Procurement Directorate, telephone number 071 636 6811 x 3284.

NHS Procurement Directorate Research Programme: Listings of Commissioned Research

Entries are divided into four parts. Parts A and B list units and programmes administered by NHS authorities and other agencies, respectively. Parts C and D list single projects administered by NHS authorities and other agencies, respectively. The dates shown relate

to the total period of support; the figures in brackets show the amount of DH funding for 1989/90. Words and phrases highlighted in ***bold italics*** are explained in the *Guide to Terms* on page ix. *E* denotes a provisional figure only.

A. Units and Programmes Administered through NHS Authorities

WEST MIDLANDS REGIONAL HEALTH AUTHORITY

Shropshire Health Authority

Orthotics Research and Locomotor Assessment Unit
Robert Jones and Agnes Hunt Orthopaedic Hospital
Oswestry SY10 7AG
(0691 655311)

7.1. Director: Mr J H Patrick

Orthotics Research Programme

The unit is carrying out a programme of research and development related to orthotic equipment. Previous suc-

cessful innovations have included a range of swivel walkers, and the Hip Guidance Orthosis (HGO), which enables paraplegic patients to walk with reciprocal gait.

Current work focuses on the application of ***Functional Electrical Stimulation*** (FES) to reduce the energy costs involved in walking using the HGO; and on the use of gait analysis and precisely-adjusted lower limb orthoses to help cerebral palsied children to walk.

1985-1990 (1989/90: £198,286) *E*

B. Units and Programmes Administered through Other Agencies

UNIVERSITY OF LONDON

University College London

Bio-Engineering Centre
Roehampton Lane
London SW15 5PR
(081 789 6500)

7.2. Deputy Director: Dr M E Dewar

Prosthetics and Orthotics Research Programme

The Centre is coming to the end of a research and development programme in prosthetics and orthotics. The most significant single project within that programme has been the

application of CAD/CAM systems to the production of thermo-plastic sockets for artificial limbs.

A system has been developed which captures the shape of the amputee stump, manipulates it using an ***expert system*** to achieve the best socket shape, and vacuum-forms the final socket over a positive shape, produced with a numerically-controlled machine-tool.

System software for below-knee sockets has been produced and software for above-knee amputations is currently being refined. The Department has granted licences to two manufacturers for commercial exploitation of the system.

1980-1990 (1989/90: £277,819)

C. Single Projects Administered through NHS Authorities

NORTH EAST THAMES REGIONAL HEALTH AUTHORITY

Bloomsbury Health Authority

Royal National Orthopaedic Hospital
Brockley Hill
Stanmore
Middlesex HA7 4LP
(081 954 2300)

7.3. Director: Professor P S Walker

Testing the Mechanical Characteristics of Uncemented Hip-Stem Components: Formulation of a Method

This project is formulating a method for testing the mechanical characteristics of uncemented hip-stem components, in order to assess their safety in clinical applications.

Manufacturers will be able to use the method both to demonstrate that their stems meet safety requirements and, if they wish to recommend the design as being particularly suited to more rigorous cases, to test beyond the standards. 1989–1990 (1989/90: £22,766) *E*

SOUTH EAST THAMES REGIONAL HEALTH AUTHORITY

Brighton Health Authority

Chailey Heritage Hospital
North Chailey
nr Lewes BN8 4EF
(082 572 2112)

7.4. Director: Mr R L Nelham

Development of an Improved Adjustable Standing-frame Design

This project aims to develop a new, adjustable, folding standing-frame for handicapped children, adolescents and some adults — including those with orthopaedic deformities. The design of the frame incorporates a range of essential support features, which, as well as preventing further deformity, provide an alternative, but therapeutically correct, posture.

A prototype frame is being produced in conjunction with therapists, using, where possible, the principles and some of the components developed for the Chailey Adaptaseat. Evaluation of the design will concentrate on the effectiveness and ease with which the frame positions and supports clients with cerebral palsy.

1989–1990 (1989/90: £2,877)

SOUTH WESTERN REGIONAL HEALTH AUTHORITY

Bristol and Weston Health Authority

Bristol General Hospital
Department of Medical Physics
Guinea Street
Bristol BS1 6SY
(0272 265001)

7.5. Directors: Professor P N T Wells, Dr P C Jackson

The Quality of Flow Data from Magnetic Resonance Imaging (MRI)

MRI produces high-quality anatomical images with good soft tissue contrast; planar 2-dimensional images taken from any angle can be obtained and 3-dimensional imaging is becoming common. A significant advantage of MRI is that prolonged studies are possible, whereas X-rays must be used sparingly. As well as physical features, the technique provides a wide range of *in vivo* information, including chemical composition, biochemical status and fluid flow rates. Fluid flow and blood-vessel mapping are being developed by manufacturers and a number of research groups.

This project aims to assess the accuracy, precision and limitations of the techniques available, especially for blood vessels where there may be a pulsatile and/or disturbed flow. It will also evaluate the clinical use of MRI in measuring flow, and will develop methods of assessing the 'artefacts', caused by movement, which appear in MR images.

An apparatus (*flow-rig*), capable of producing constant velocities, has been built and preliminary results obtained. It is now being extended to allow the investigation of non-uniform flow: clinical studies have started.

1988–1992 (1989/90: £18,616) *E*

SOUTH WEST THAMES REGIONAL HEALTH AUTHORITY

Wandsworth Health Authority

St George's Hospital
Department of Medical Physics and Bio-Engineering
Blackshaw Road
London SW17 0QT
(081 672 1255)

7.6. Directors: Dr D K Nassiri (St George's), Dr R Preston (NPL)

Development of Standard Layered-Tissue Models for the Assessment of 'In Situ' Acoustic Levels in Ultrasound Diagnosis

Jointly funded by DH and DTI, the project is developing a set of standard layered-tissue models, including physical and acoustic data relating to each layer of tissue at each selected imaging-site. The combined effects of each layer can then be used to determine, as accurately as possible, the ultrasound exposure received deep in tissue, at the selected site, and relate it to that transmitted from the scanner at the skin surface.

The results will be used to recommend limits for safe exposure to the ultrasound scanning equipment, the parameters of which are measured in a water bath.

1990–1992 (1989/90: £9,000)

TRENT REGIONAL HEALTH AUTHORITY

Leicestershire Health Authority

Grobby Road Hospital
Leicestershire LE3 9QE
(0533 874141)

7.7. Director: Mr J S Bailey

Acoustic Assessment of Malfunction in Mechanical Prosthetic Heart Valves

Some 5,000 heart valve replacements are carried out in the UK every year, about 65 per cent of which use mechanical valves. One complication that can arise with this type of implant is the formation of blood clots (thrombi) on the valve surface, which can impair valve function and lead to thrombo-embolism. Careful management of anti-coagulation therapy is therefore essential to the long-term post-operative care of patients with mechanical valves.

A system has been developed for recording and analysing the high frequency sounds mechanical valves make when they open and close, and work *in vitro* has established that small deposits of material on the valve can cause marked changes in the pattern of sounds detected. The technique is therefore potentially useful in diagnosing valve malfunctions and in fine-tuning anti-coagulation therapy.

This project is a clinical evaluation of the technique, and aims to establish its ability to identify valve malfunction or thrombus formation, in patients attending anti-coagulation clinics.

1988–1990 (1989/90: £42,997)

Sheffield Health Authority

Royal Hallamshire Hospital
Glossop Road
Sheffield S10 2JF
(0742 766222)

7.8. Director: Professor B H Brown

Electrical Impedance Imaging of Applied Potential Tomography (APT)

APT involves the measurement of variations in resistance to electric current flow in different tissues, when a number of electrodes are placed on the skin in the area of the body to be imaged. Compared with the more conventional X-ray, **Computed Tomography**, and **Magnetic Resonance Imaging**, the images are sometimes distorted and difficult to interpret, but diagnostic information can be observed.

The aims of this project are to reconstruct images from the complicated measured impedances, and evaluate APT in the detection of intra-ventricular haemorrhages in low birth-weight neonates, and the investigation of cardio-pulmonary functions.

Mark II equipment has been developed and used for heart and lung studies, and data have been collected on neonates undergoing lumbar puncture.

1987–1991 (1989/90: £29,642)

WESSEX REGIONAL HEALTH AUTHORITY

Bath District Health Authority Salisbury Health Authority

Royal United Hospital
Bath BA1 3NG
(0225 28331)

Salisbury General Hospital
Odstock Branch
Salisbury SP2 8BJ
(0722 336262)

7.9. Directors: Professor S Lillicrap, Dr J Russell

Development and Evaluation of Functional Electrical Stimulation (FES) Orthosis for Spinal-Cord-Injured Patients

By applying appropriate impulses, **FES** is potentially capable of restoring action to paralysed muscle. The research team at Odstock Hospital has developed a stimulation system which successfully enables paraplegic patients to rise from a sitting to a standing position. Portable microprocessor-based systems have been built and are being used by patients; a trial using 20 systems will be carried out during this project.

1988–1991 (1989/90: £29,457)

D. Single Projects Administered through other Agencies

LEICESTER POLYTECHNIC NATIONAL HOSPITAL FOR NERVOUS DISEASES

School of Computing and Mathematical Sciences

Leicester LE1 9BH
(0533 551551)

Institute of Neurology

Queen Square
London WC1N 3BG
(071 837 3611)

7.10. Directors: Professor D Teather, Professor G duBoulay

An Expert System to assist in Diagnostic Interpretation of Computed Tomography and Magnetic Resonance Images

A computerized **expert system** has been developed as a teaching aid in the interpretation of **Computed Tomography** (CT) images and is now being extended to **Magnetic Resonance Imaging** (MRI).

MRI is a complex procedure, with a vast range of data-acquisition protocols. The choice of image-sequence type and parameters is crucial to the kind of image produced, the contrast achieved and, therefore, its diagnostic value.

The aim of this research is to develop an **expert system**, designed to run on a personal computer, to help in making the choices for a particular referral diagnosis, and to assist subsequent diagnosis of the MR images obtained.

1989–1991 (1989/90: £13,676)

PUBLIC HEALTH LABORATORY SERVICE

Bowthorpe Road
Norwich NR2 3TX
(0603 611816)

7.11. Director: Mr S Line

The Inactivation of Pathogenic Micro-Organisms by Low Temperature Steam (LTS)

The aim of this project was to determine the antimicrobial effect of LTS. Work was carried out to identify the most satisfactory time and temperature relationships to be used, during an LTS cycle, to inactivate an infectious (pathogenic) organism. Having selected a resistant bacterium — *Streptococcus faecalis* NCTC 8619 — its survival in heat, measured both in LTS and in aqueous suspension, was measured and found to be similar. It was concluded that heat sensitivity data obtained from the aqueous solution could be assumed to apply to LTS inactivation also. The project is now complete.

1986–1989 (1989/90: £15,604)

61 Colindale Avenue
London NW9 5HT
(081 200 4400)

7.12. Director: Professor E M Cooke
Contact: Dr P Mortimer

Using Heat and Chemical Disinfectants to Inactivate HIV

The aim of this project, jointly funded with the Health and Safety Executive (HSE), is to evaluate the effectiveness of heat, and of chemical disinfectants, in inactivating HIV. The results will determine what measures are adopted in decontaminating instruments and equipment which have been in contact with infected patients' body fluids.

The researchers have established methods to enable a standardized and reproducibly high titre of the virus to be grown in culture, and to allow reliable and reproducible **assay** in tissue culture.

Studies on the effectiveness of heat to inactivate virus in serum have allowed the *D value* (that is, the time taken for a ten-fold reduction in infectivity) to be determined at various temperatures. Tests have been carried out to assess the effectiveness of alcohol in inactivating the virus. The ability to recover the virus, following drying, has also been investigated.

1987–1990 (1989/90: £18,828)

ROYAL MILITARY COLLEGE OF SCIENCE

Shrivenham
Swindon SN6 8LA
(0793 782551)

7.13. Director: Professor R A King

Development of Prosthetic Languages for Speech-Impaired People

This project aims to construct *prosthetic* (artificial) languages for severely speech-impaired individuals. Computerized speech-recognition equipment has been developed, capable of recognizing limited sets of utterances (not necessarily speech-like) which can be made controllably by people — such as some with cerebral palsy — who cannot achieve understandable speech.

The system helps to select utterances which are discriminable even under the most adverse conditions, and use these as phonemic blocks to which meaning is assigned, singly and in combination: machine translation of the recognized utterance-set is directly available. The prototype system has operated with one patient and wider trials are to take place during 1990.

1987–1990 (1989/90: £127,635)

UNIVERSITY OF BATH

Claverton Down
Bath BA2 7AY
(0225 826500)

7.14. Directors: Dr D J G Davies, Dr C J Soper

Development, Characterization, Production and Recovery of a Biological Indicator Organism for Low-Temperature Steam/ Formaldehyde Sterilization (LTSF)

Reliable validation of an LTSF cycle requires the monitoring of temperature, pressure, and concentration, distribution and penetration of formaldehyde. Owing to the complexity of the study, physical monitoring is difficult to achieve economically. Biological monitors are used at present, but no monitor has yet been developed specifically for LTSF.

This project has aimed to develop a monitor, and studies to date suggest that spores of *Bacillus stearothermophilus* NCIB 8224 possess many characteristics which make it an ideal indicator-organism. It can be readily produced, with good within and between-batch reproducibility, and easily harvested; it has a high germination index and exhibits similar survival patterns in both formaldehyde in aqueous solution, and in LTSF.

1986–1989 (1989/90: £9,226)

UNIVERSITY OF
EDINBURGH

Department of Pathology
Old College, South Bridge
Edinburgh EH8 9YL
(031 667 1011)

and

UNIVERSITY OF NIJMEGEN

Department of Pathology
Nijmegen
The Netherlands
(080 51 6931)

MEDICAL RESEARCH COUNCIL

Human Genetics Unit
Northern General Hospital
Ferry Road
Edinburgh EH5 3DQ
(031 332 2525)

7.15. Directors: Professor C Bird, Professor G P Vooijs, Dr D Rutovitz

Cervical Smear Screening by Machine Analysis of Nuclear Shape and Density in Automatically-Prepared Monolayers

In this project, monolayer smears of cervical material are produced using apparatus developed by the University of Nijmegen. These are stained using different methods, and assigned a *consensus classification* by cytopathologists from the Universities of Edinburgh and Nijmegen.

The smears are then classified, using a computerized pattern-recognition system initially developed by the MRC, and the results of the two classification methods are compared.

1989–1990 (1989/90: £21,171)

UNIVERSITY OF LEEDS LONDON HOSPITAL
MEDICAL COLLEGE

Leeds LS2 9JT Turner Street
(0532 431751) London E1 2AD
 (071 377 7628)

7.16. Directors: Professor I Ward, Professor M Braden

Development of High Modulus Polyethylene for Reinforced Dental Materials

This research achieved early technical success with the production of dentures reinforced with a mat of *high modulus polyethylene*, which has high impact strength. Dentures are frequently broken and swallowed in vehicle accidents and one advantage of the mat is that the fragments are held together, preventing dentures from being swallowed. Clinical trials have been highly successful.

The project has concentrated on using fibre-reinforced high modulus polyethylene to form orthodontic brackets which are cheaper and more aesthetically acceptable than metal ones. The processing and characterization of the mechanical properties of materials for such brackets have also been examined. Further applications for these polymers include dental inlays and onlays.

The project has been extended for a year to allow new treatment of materials to be assessed, further mechanical characterization and to investigate commercial viability.

1987–1990 (1989/90: £22,238)

UNIVERSITY OF LONDON

Imperial College of Science and Technology
Prince Consort Road
London SW7 2AZ
(071 589 5111)

7.17. Director: Dr C N Guy

Multi-Channel System to Detect Biomagnetic Fields

Super-conducting Quantum Interference Devices (SQUIDS) are very sensitive to magnetic fields and can detect the minute fields generated by the small electric currents produced by activity in the brains and hearts of living organisms. The technique is called Magneto-Encephalography (MEG) and Magneto-Cardiography (MCG) — in parallel with Electro-Encephalography (EEG), which records voltages — and its ability to detect biomagnetic fields extends the scope of data which can be observed.

This research aims to develop low-cost systems which can monitor and localize neural activity in processes such as thought activity during speech and hearing, and in epileptic seizures, where more precise localization than that provided by EEG has improved surgical accuracy.

1986-1990 (1989/90: £8,561)

King's College London
Denmark Hill
London SE5 8RX
(071 274 6222)

7.18. Director: Professor V C Roberts

Direct and Shear Stresses on Amputee Stumps

The fit of a socket to the amputee's stump is crucial to the use and comfort of an artificial leg, and a better understanding of the dynamics of this should enable more effective socket types to be designed.

The first stages of this project have developed a slim *transducer*, which is set into the wall of a thermoplastic socket, to measure pressure and shear simultaneously.

Work now focuses on incorporating an array of transducers into a socket, with metering and data-logging equipment, so that variations in pressure and shear forces can be studied as the user walks on the artificial limb.

1986–1990 (1989/90: £56,880)

NORTH WEST THAMES REGIONAL HEALTH AUTHORITY

London Postgraduate Teaching Hospitals
National Heart and Chest Hospital
Brompton Hospital
Fulham Road
London SW3 6HP
(071 352 8121)

Riverside Health Authority
St Stephen's Hospital
Fulham Road
London SW10 9TH

7.19. Directors: Dr J Collins, Dr P Hanson

Preventing HIV Transmission by Fibre-Optic Instruments

The aim of this project has been to determine minimum requirements for the safe disinfection and cleaning of fibre-optic instruments contaminated with micro-organisms which cause diseases such as AIDS and tuberculosis.

Tests included assessing the effectiveness of disinfectant preparations and cleaning procedures in eliminating or reducing microbial contamination, and were conducted on those instruments which had been used to investigate patients' symptoms, as well as those deliberately contaminated in the laboratory.

Fresh solutions of 2 per cent alkaline glutaraldehyde were found to be effective against dried HIV, but 70 per cent alcohol was inappropriate for surface disinfection of HIV — see *British Medical Journal*, **298** (1989) 862–864.

1987–1990 (1989/90: £16,725) *E*

UNIVERSITY OF LONDON

London School of Hygiene and Tropical Medicine
University College
Keppel Street
London WC1E 7HT
(071 636 8636)

Royal Free Hospital
School of Medicine
Rowland Hill Street
London NW3 2PF
(071 794 0500)

7.20. Directors: Professor A Zuckerman, Dr K Tsiquaye

Use of Heat and Chemical Disinfectants to Inactivate Duck Hepatitis Virus

Jointly funded with the HSE, this project is evaluating the effectiveness of various chemicals and physical methods in rendering safe potentially infectious body fluids and contaminated instruments. Viral activity is assessed by determining DNA polymerase activity; infectivity is determined by an *in vivo* system in which duck hepatitis virus is used as a model for the human Hepatitis B Virus (HBV). The tests carried out include assessing the effectiveness of disinfectants and heating against the virus suspended in serum and whole blood.

1988–1990 (1989/90: £19,976)

University College London

University College and Middlesex School of Medicine
11–20 Capper Street
London WC1E 6JA
(071 380 9700)

7.21. Director: Professor J Clifton

Development of a Fibre-Optic Laser Ultrasound Sensor

When a pulse of laser energy interacts with tissue, an acoustic shock wave is produced by the dissipation of energy where the interaction takes place. This acoustic output can be detected using a small **transducer**, fused to the end of a fibre-optic catheter.

Various types of tissue produce different responses so, by making a profile of the acoustic *signatures* of types of materials — for example, bone, arterial wall and arterial plaque — it is possible to detect which type of tissue is directly in the path of the laser. The laser energy and the sensor signal can be passed through one very-small-diameter fibre, enabling arterial obstructions to be discerned in blood vessels as little as one millimetre in diameter — such as the coronary artery.

Preliminary results show that the system is viable, although very low signal levels from the fibre **transducer** have been making measurements difficult.

1988–1989 (1989/90: £4,498)

University College London

Gower Street
London WC1E 6BT
(071 387 7050)

7.22. Director: Dr A D Linney

Assessment of Periodontitis by Computer Radiography

The purpose of this work is to develop software that uses commercially-available hardware to compare X-ray photographs taken at various times over several months. The two main problems are relating the intensity of the image, and geometrical changes in tooth position. Using such measurements, the dentist is able to monitor the progress of periodontitis.

The technical feasibility of the system has now been demonstrated and other applications, dental and non-dental, are envisaged. A commercial partner is currently being sought, to make the software user-friendly and ensure that it is made available to patients.

1986–1990 (1989/90: £20,324)

UNIVERSITY OF LONDON NORTH EAST THAMES
REGIONAL HEALTH
AUTHORITY

University College London Bloomsbury Health Authority
Department of Geriatric St Pancras Hospital
Medicine 4 St Pancras Way
Gower Street London NW1 9PE
London WC1E 6BT (071 387 4411)

7.23. Directors: Dr A Cottenden, Dr J Malone-Lee

Evaluation of Absorbent Incontinence Aids

Four categories of incontinence pad — disposable and re-usable, body-worn and bed-pads — are being assessed in this project, using both clinical and technical testing. Correlations between the two will be identified to assist in preparing functional standards.

The study of disposable body-worn pads is being carried out in conjunction with an international evaluation set up by the International Standards Organization (ISO) to prepare standards. The international project is being organized, and the results analysed, by a team at St Pancras Hospital: the results will be added to those of the UK project, to provide a much wider information base.

The project is due to be completed early in 1991 and will provide information of value to the incontinence services and to industry in their development of improved products.

1988–1990 (1989/90: £9,878)

UNIVERSITY OF MANCHESTER

Oxford Road
Manchester M13 9PL
(061 275 2172)

7.24. Director: Dr T A King

Development of an Erbium Laser

The carbon dioxide (CO₂) laser has a wavelength of 10.6 micrometres and is used as a cutting device in general surgery. Its use is restricted because there is currently no suitable fibre for transmitting the energy, making it impossible to cut tissue with this laser when working with a flexible endoscope.

Instead of trying to produce a fibre for CO₂, this research has been examining an alternative method — using the Erbium wavelength of 2.94 micrometres. This can be transmitted down a fibre, and has a better cutting characteristic than CO₂. Results to date show that the laser is a very precise cutter, barely damaging the tissue surrounding the site. However, as a crystal laser, it is less efficient and more expensive to construct; and because excessive input-energy causes crystal fracture, power is restricted.

Two lasers are currently being used for microsurgery, and other applications are being investigated.

1987–1989 (1989/90: £62,586)

UNIVERSITY OF SURREY

Guildford
Surrey GU2 5HX
(0483 571281)

7.25. Director: Mr S Hughes

Bibliography of Pressure Sores

The aim of this project is to produce a bibliography of publications which provide quantitative information on pressure sores and pressure sore research. Approximately 3,500 publications have been reviewed, of which about 10 per cent were found to contain quantitative information.

The project is just complete and the bibliography is available from the University of Surrey on IBM-compatible computer disk. The bibliography will be updated regularly by the University as more papers are published.

1987–1990 (1989/90: £7,929)

UNIVERSITY OF WALES

College of Medicine

Department of Epidemiology and Community Medicine
Heath Park
Cardiff CF4 4XN
(0222 755944)

7.26. Director: Dr I P Matthews

Development of a Monitoring and Control System for Ethylene Oxide Sterilization

The objective of this 2-year project is to develop equipment that will be capable of measuring and monitoring the levels of humidity, ethylene oxide concentration and the temperature within the load of an ethylene oxide sterilizer. The measurement of humidity and ethylene oxide concentration is based on microwave technology, and the measurement of temperature on a liquid-crystal material and fibre-optic technology.

Currently, release of a load passing through an ethylene oxide sterilizer is dependent upon the fairly lengthy *assay* of biological monitors. With the successful development of this equipment, the possibility of parametric release — as practised in steam sterilization processes — becomes much more of a possibility.

The first report of this two-year project has now been received, and indicates that a prototype has been successfully built for the ethylene oxide measurement, which keeps the project on target.

1989–1990 (1989/90: £3,791)

UNIVERSITY OF WALES		UNIVERSITY HOSPITAL OF WALES	UNIVERSITY OF YORK
Welsh School of Pharmacy		Public Health Laboratory	Heslington
PO Box 13		Mycobacterium Reference	York YO1 5DD
Cardiff CF1 3XF		Unit, Heath Park	(0904 59861)
(0222 874000)		Cardiff CF4 4XW	7.28. Director: Professor A Williams
		(0222 755944)	<i>An Economic Evaluation of Clinical Magnetic Resonance Imaging</i>
7.27. Directors: Dr A D Russell, Dr J R Furr, Dr P A Jenkins			This is a joint project with the MRC to determine the economic advantages and disadvantages of using Magnetic Resonance Imaging (MRI) . A small number of collaborating sites supplied information on examinations to the Centre in York. This information included reasons for referral, initial diagnosis, diagnosis following MR examination, outcome, and details of other procedures (especially Computed Tomography).
<i>Evaluation and Assessment of Mycobactericidal Activity</i>			One of the problems the researchers now face is the rapid development of the technique itself. The data were collected on an early-generation system — at low magnetic field strengths — which is much less efficient than current commercial systems.
The aims of this project are to devise reliable and reproducible test methods for evaluating the activity of disinfectants against <i>mycobacteria</i> , and to investigate the reasons why these organisms demonstrate resistance to disinfectants.			1985–1989 (1989/90: £31,542)
The project started recently, and initial studies have demonstrated some variance in the sensitivity of different strains of <i>mycobacteria</i> .			
1989–1992 (1989/90: £3,950)			

Chapter 8

Publications

The chapter, which details publications resulting from research funded by the Department of Health, is divided into four parts. Part A lists books, articles, monographs, et cetera, published in 1989 and based

on research which was completed in 1988 or earlier. Part B gives publications from ongoing research. Publications resulting from IT and Procurement Directorate research are found in parts C and D respectively.

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Appendix 1

International Research: UK Representatives

The following represent the United Kingdom at regular meetings of EC research committees, or give advice to the Department:

MEDICAL AND HEALTH RESEARCH PROGRAMME

1. Main management committee

Dr D Evered BSc MB MRCP MD FRCP FRSM
Mr J Barnes MSc

2. Epidemiology

Professor C du Ve Florey MDMPH FFCM
Dr Elizabeth Russell MD FSCM MRCP

3. Health Services Research

Mr M J Buxton BA (Soc Sci)
Dr M Cuthbert OBE BSc FRCOG

4. Biology

Professor L Wolpert (Chair) DIC PhD FRS
Professor W MacDonald PhD FRCP FIBiol
Professor R F Mahler BSc FRCP FRCPE

5. Biomedical Engineering

Professor B H Brown BSc PhD CPhys SInstP CEng MIEE
Professor J Edwards FRCP FRS

6. Cancer

Professor N M Bleehen BA BSc MA BM BCh MRCP
FRCP FRCR DMRT
Professor M J Crumpton PhD FRS

7. AIDS

Dr A Glynn MD MB BS FRCP FRCPath/Dr N Gill
Dr G C V Schild PhD FIBiol
Dr J Cope PhD

RADIATION PROTECTION RESEARCH PROGRAMME

1. Main Management Committee

Dr H Walker BSc MSc PhD CBiol MIBiol FRGS
Dr J Dennis ARCS BSc PhD FInstP

2. UK Experts Advisory Group

Professor G Adams PhD DSc FACR
Mr P Beaver BSc MInstP CPhys FINUCE
Professor R Berry MD DPhil FRCP FRCR
Dr K Duxbury PhD
Dr A E Eggleton BSc PhD
Mr G Meekings BSc MInstP
Mr F Spencer PhD
Mr B Walters LRCP LRCS LRFPS

ADVANCED INFORMATICS IN MEDICINE (AIM)

Mr C M O'Rourke

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